



## DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

### Doctorate in Clinical Psychology: Main Research Portfolio

**1) Literature Review: Compassion-focused therapy for trauma in people with learning disabilities: a conceptual review; 2) Service Improvement Project: How stroke patients and carers experience an early supported discharge service: service improvement driven by service-user perspectives; 3) Main Research Project: An experimental investigation into the effect of state-anxiety on state-paranoia in people experiencing psychosis.**

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# Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

University of Bath  
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## **Abstracts**

### **Literature Review**

Trauma-exposure and post-traumatic stress disorder are more prevalent in people with learning disabilities than in the general population, yet the evidence-base regarding effective interventions for trauma in this population is sparse. Research shows that compassion-focused approaches are effective at improving client outcomes for a range of difficulties, and emerging evidence suggests that compassion-focused therapy for trauma is a promising approach in the general population. Compassion-focused therapy may be well suited to people with learning disabilities for a number of reasons, including its adaptability to different developmental levels. People with learning disabilities who have been traumatised may be more likely to have issues with self-relating and attachment, two issues that compassion-focused therapy explicitly seeks to address. Furthermore, compassion-focused approaches emphasise cultivating a sense-of-safety whilst empowering people to make behavioural changes; this is particularly pertinent to people with learning disabilities who have been traumatised and may feel unsafe and dis-empowered. A brief overview of compassion-focused therapy and its application to trauma are given, as well as some case studies using compassion-focused therapy with people with learning disabilities. It is argued that compassion focused therapy warrants further investigation as a potential framework from which to support people with learning disabilities who have been traumatised. It is also suggests that organisations that work with people with learning disabilities should aim to deliver compassionate, trauma-informed care guided by compassion focused therapy. Future directions are discussed.

### **Service Improvement Project**

Early supported discharge (ESD) services provide intensive, community rehabilitation for people after a stroke. 10 patient and 6 carer interviews were conducted and analysed using thematic analysis to explore service-user experiences of an Early Supported Discharge (ESD) service. The results show that the team provides a high quality service that is well respected by service-users. It was apparent that, although well planned, endings were a difficult experience for patients. Both patients and carers discussed uncertainty about the future. Emotional support was reported to be particularly valuable; this was provided generally by all staff and more specifically by psychologists and counsellors when indicated. Recommendations for the service included: endings being

discussed with service-users at the start of the team's involvement; conducting an endings meeting and developing an endings leaflet; developing a personalised 'My next steps' sheet to provide clarity for service-users about moving out of the service; revisiting how review meetings are conducted; and bi-annual psychology training days for staff. Many recommendations have already been implemented by the service. Limitations and future directions are discussed, as well as recommendations for other ESD services.

## **Main Research Project**

*Background and Objectives:* The threat-anticipation model of paranoia suggests that a number of factors interact to form and maintain paranoia, with anxiety playing a key role. There is strong evidence to suggest that anxiety is associated with paranoia in clinical and non-clinical samples. However, no research to date has directly manipulated anxiety to investigate if state-anxiety has a causal role in state-paranoia in clinical populations.

*Methods:* 22 participants with a psychosis-spectrum diagnosis took part in a repeated-measures, experimental, cross-over design. Participants took part in a neutral-mood and an anxious-mood induction with levels of state-anxiety, state-affect and state-paranoia being measured before and after each condition.

*Results:* State-paranoia was significantly higher after the anxious condition compared to the neutral condition. State-anxiety and state-paranoia were significant predictors of levels of state-paranoia after the anxious condition. When both predictors were included in a regression model, only negative-affect was a significant predictor of state-paranoia after the anxious condition.

*Limitations:* There were a number of methodological limitations that are outlined in the discussion.

*Conclusions:* State-anxiety and negative-affect may both be involved in the maintenance of paranoia in clinical populations, as predicted by the threat-anticipation model. However, negative-affect may be more important in state-paranoia than state-anxiety in clinical populations. Interventions that seek to reduce state-affect may be beneficial in managing state-paranoia. Further research is warranted to explore the suggested clinical and theoretical implications of these findings.

## Word Counts

Literature Review.....	7225
Service Improvement Project.....	4939
Main Research Project.....	5602
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# **Compassion-Focused Therapy for Trauma in People with Learning Disabilities: A Conceptual Review**

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## **Abstract**

Trauma-exposure and post-traumatic stress disorder are more prevalent in people with learning disabilities than in the general population, yet the evidence-base regarding effective interventions for trauma in this population is sparse. Research shows that compassion-focused approaches are effective at improving client outcomes for a range of difficulties, and emerging evidence suggests that compassion-focused therapy for trauma is a promising approach in the general population. Compassion-focused therapy may be well suited to people with learning disabilities for a number of reasons, including its adaptability to different developmental levels. People with learning disabilities who have been traumatised may be more likely to have issues with self-relating and attachment, two issues that compassion-focused therapy explicitly seeks to address. Furthermore, compassion-focused approaches emphasise cultivating a sense-of-safety whilst empowering people to make behavioural changes; this is particularly pertinent to people with learning disabilities who have been traumatised and may feel unsafe and dis-empowered. A brief overview of compassion-focused therapy and its application to trauma are given, as well as some case studies using compassion-focused therapy with people with learning disabilities. It is argued that compassion focused therapy warrants further investigation as a potential framework from which to support people with learning disabilities who have been traumatised. It is also suggests that organisations that work with people with learning disabilities should aim to deliver compassionate, trauma-informed care guided by compassion focused therapy. Future directions are discussed.

## **Overview**

There is a dearth of literature or clear guidance about how best to support people with learning disabilities (PWLD) who have experienced trauma. Compassion-focused therapy (CFT) was developed to support people experiencing shame and self-criticism, often due to exposure to trauma, adversity and attachment difficulties (Gilbert, 2010b). Given the prevalence of traumatic experiences in PWLD (Hughes et al., 2012; Jones et al., 2012), and the increased likelihood for attachment difficulties (Janssen, Schuengel, & Stolk, 2002), CFT seems particularly well placed to address their needs. CFT is accessible for clinicians and can complement other evidence-based approaches. Many of the techniques used in CFT are skills-based and readily modifiable to suit differing developmental levels. CFT for trauma can be used to develop stabilisation and grounding strategies, as well as engaging with trauma memories and flashbacks (Lee, 2012). Additionally, the focus of CFT on affiliation and compassionate self- and other-relating lends itself as an overarching approach to healthcare provision and service culture (Cole-King & Gilbert, 2014). This paper will further explore the points raised above and discuss case examples of using CFT with PWLD and the services around them as a springboard from which further research might be developed.

## **Process and Structure of this Review**

This review began in response to the lead author's observations, whilst working in a community learning disability team in the UK, that trauma was often present in the histories of service-users but that many clinicians lacked confidence or knowledge about how to address it. A scoping review of the literature regarding trauma in PWLD was conducted (Databases: PudMed, PsycInfo; Search Terms: ["intellectual disab"\* OR "learning disab"\*] AND [trauma\* OR PTSD OR victim\* OR abuse\*]). Review papers and key papers of interest were interrogated. In line with the authors' clinical experience, it was evident that trauma exposure and clinically significant distress in response to this were higher for PWLD than the general population. The reviews and subsequently-published papers regarding psychological interventions for trauma showed this field to be considerably under-developed compared to the literature base for trauma-interventions in the general population. The 'Introduction' section of this paper outlines the key findings from this literature review.

The lack of clear guidelines around addressing trauma-reactions in PWLD suggests that exploration of new approaches in this domain is warranted. New approaches are being

developed for psychological distress more generally in PWLD including cognitive analytic therapy, solution focused therapy and dialectical behavioural therapy (Beail, 2016). To the authors' knowledge, based on a scoping review (Databases: PudMed, PsycInfo; Search Terms: ["intellectual disab"\* OR "learning disab"\*] AND [compassion\*]), no research regarding the use of CFT for PWLD has been published, despite this approach being rapidly developed in the general population. The theoretical basis for the development of CFT is well-matched to the experiences that many PWLD have had, especially those who have been traumatised, and CFT lends itself well to being adapted for differing developmental levels. More recently, CFT has been adapted specifically for trauma in the general population. Based on these considerations, it was decided that a conceptual review would be appropriate, outlining why CFT could be useful for addressing trauma in PWLD. The 'Compassion Focused Therapy' section of this paper gives an outline of the theoretical underpinnings and clinical applications of CFT generally and in the context of trauma, whilst highlighting the relevance and applicability to PWLD.

The final sections of this conceptual review outline why further research into CFT for trauma in PWLD is warranted, taking the previous sections into consideration. This section draws on research around mindfulness in PWLD as well as clinical case studies of CFT being used with a range of presentations related to trauma with differing levels of service-user ability and engagement. Additionally, the potential for CFT to be used as a framework to encourage compassionate caregiving from the systems around PWLD, keeping the likelihood of trauma exposure in mind, is explored. Potential barriers and next steps are also addressed.

## **Introduction**

### **Mental Health Prevalence in PWLD**

Research has found that PWLD are at greater risk of mental health problems. A methodologically-rigorous population-based study found a 41% point prevalence of psychiatric diagnoses in adults with LD (Cooper, Smiley, Morrison, Williamson, & Allan, 2007), compared with 23% of the general adult population (McManus, Meltzer, Brugha, & Bebbington, 2009). Data from a large national survey showed that 36% of children with a learning disability had a psychiatric disorder, compared with 8% of children without a learning disability (Emerson & Hatton, 2007). Cooper and colleagues (2007) found that the factors independently associated with mental health in PWLD were largely similar to risk factors in the general population; this included experiencing a higher number of preceding

life events, which has been found to predict psychological problems in adults with LD, even after controlling for other correlates (Hulbert-Williams et al., 2013).

## **Trauma in PWLD**

### **Prevalence of Traumatic Experiences**

The life events that are most researched as predictors of mental health are those that have been experienced as traumatic. What constitutes a traumatic event is variously defined, but is commonly taken to refer to events that significantly threaten a person's sense of safety and to which they have an intense emotional response that it is difficult to integrate with their previous experiences (e.g. Saakvitne, Gamble, Pearlman, & Lev, 2000). Reviews of the literature have demonstrated that PWLD experience more traumatic events (Horner-Johnson & Drum, 2006; Hughes et al., 2012; Jones et al., 2012; Leeb, Bitsko, Merrick, & Armour, 2012). In a population-based epidemiological study it was found that 28% of children with a learning disability had been maltreated, compared to 9% of children without LD (Sullivan & Knutson, 2000). The World Health Organisation found that both children and adults with LD had a higher prevalence of exposure to maltreatment and a higher risk of maltreatment than their non-disabled peers (Hughes et al., 2012; Jones et al., 2012).

### **Increased Vulnerability to Traumatic Experiences**

Three core issues have been highlighted as making children with LD particularly vulnerable to traumatic events (Westcott & Jones, 1999): (1) dependency: PWLD often have a lifelong dependency on others to provide care, increasing opportunities for abuse to take place (Westcott & Jones, 1999). Furthermore, routine care activities may be carried out in ways that are experienced as traumatic (Westcott & Cross, 1996); (2) institutional care: PWLD may spend extended periods of time in hospitals, residential settings and special schools where staff are often underpaid and poorly trained (Department of Health, 1997). The Winterbourne View scandal is one example of the systemic failings that can occur in such settings (Department of Health, 2012), although it is far from the only residential service that has fostered a culture of abuse (e.g. Cambridge, 1999). Data shows that in the majority (29.6%) of referrals for suspected abuse in PWLD the alleged perpetrator was a member of social care staff (Hatton et al., 2013); (3) communication: exposure to trauma, especially abuse, can be difficult for people to talk about for a variety of reasons, including fear of the consequences of disclosing, guilt and self-blame, shame,

ambivalent feelings, wanting to protect the abuser, worrying they will not be taken seriously, trying to forget the trauma, and communication limitations (Allnock & Miller, 2013; Goodman-Brown, Edelstein, Goodman, Jones, & Gordon, 2003; Hegarty & Taft, 2009; Hershkowitz, Lamb, & Horowitz, 2007; Leander, 2010; Oosterhoorn & Kendrick, 2001; Paine & Hansen, 2002; Sas & Cunningham, 1995; US Department of Justice, 2000).

The relatively powerless position of PWLD in our society has also been suggested as a contributory factor to increased risk of abuse (Sobsey & Doe, 1991; Tharinger, Burrows Horton, & Millea, 1990). Additionally, a broader range of negative life events are likely to be experienced as traumatic by PWLD. For example, a negative life event such as a bereavement is more likely to result in the loss of both a home and a carer for PWLD, with an obviously heightened traumatic impact (Hollins & Esterhuyzen, 1997).

### **Post-traumatic Stress Disorder in PWLD**

A 16% prevalence of post-traumatic stress-disorder (PTSD) has been reported in PWLD (Ryan, 1994) compared to a 7.8% prevalence in the general population (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). As cumulative trauma exposure is found to predict PTSD (Briere, Agee, & Dietrich, 2016; Wilker et al., 2015), one would expect higher rates amongst PWLD. Other factors that may contribute include developmental level (van der Kolk, McFarlane, & Weisaeth, 1999), information processing difficulties (Salmon & Bryant, 2002) and cognitive coping strategies (van Nijnatten & Heestermans, 2010). Additionally, issues with communication mean that PWLD may be less able to engage with supportive discussions about traumatic events, both because of limitations in their understanding and the often inhibitory actions of those around them. This can result in their experience of the trauma becoming ‘...buried beneath feelings of shame, guilt and confusion’ (van Nijnatten & Heestermans, 2010).

### **Current Interventions for Trauma in PWLD**

Trauma-focused cognitive behavioural therapy (TF-CBT) and eye-movement desensitisation and reprocessing (EMDR) are the recommended treatments for PTSD in the general adult population (NICE, 2005). There is very limited research into effective interventions for trauma in PWLD. Reviews of the literature have predominantly identified case studies describing success in reducing trauma related symptoms with EMDR, TF-CBT, and psychodynamic psychotherapy (Mevissen & de Jongh, 2010; Mevissen, Didden, & de Jongh, 2016). Many of these case studies detail how existing protocols can be

modified to meet the specific needs of the service-user, including needs related to their learning disability and health (e.g. Barrowcliff & Evans, 2015; Carrigan & Allez, 2016; Fernando & Medlicott, 2009). However, there are no PTSD-specific guidelines for PWLD (NICE, 2016) due to the lack of methodologically rigorous research studies, such as randomised controlled trials.

Although initial research into EMDR and TF-CBT for trauma in PWLD looks promising, there are some concerns. There are ethical issues inherent in providing trauma-focused work to vulnerable people. For example, Gilderthorp (2015) outlines the potential for re-traumatisation and the complexities of gaining consent in people who have less understanding of what the therapy entails. Additionally, existing research suggests that EMDR and TF-CBT need to be highly adapted for some service-users in this population. For instance exposure to triggers, a standard feature of TF-CBT, may be contraindicated in people with more severe LD (Bakken et al., 2014). Further research is urgently needed to develop the evidence base towards tailored, accessible and effective interventions that clinicians feel confident to use.

### **The Potential Role of Compassion**

Given the prevalence and impact of trauma in PWLD, Keesler (2014) calls for organisations to deliver trauma-informed care (TIC) for this population. TIC involves a cultural shift whereby safety, trustworthiness, choice, collaboration and empowerment are central to systemic functioning among service providers and service-users (Fallot & Harris, 2009). Jennings (2004, p. 15) describes TIC as an approach that encourages:

“...an understanding of clients and their symptoms in the context of their life experiences and history, cultures, and society...an emphasis on skill building and acquisition rather than symptom management; an understanding of symptoms as attempts to cope...a focus on what has happened to the person rather than with what is wrong with the person.”

Compassion-focused therapy (CFT) aims to address the elements central to TIC. CFT uses a range of techniques to help individuals develop a greater sense of safety, trust and social affiliation, as well as formulating problems within historical, cultural, social and biological contexts. Compassion-focused approaches to care systems offer improved experiences and outcomes for staff and service-users alike (c.f. Journal of Compassionate Health Care: [jcompassionatehc.biomedcentral.com](http://jcompassionatehc.biomedcentral.com)). This review presents the conceptual

case for the utility of CFT as a framework to support PWLD at both the individual and service-wide level.

## **Compassion-Focused Therapy**

### **Background**

CFT is a transdiagnostic therapy pioneered by Professor Paul Gilbert and is rooted in evolutionary and social psychology, attachment theory, neuroscience and cognitive-behavioural therapy (Gilbert, 2014). The main focus is to encourage emotional and mental wellbeing through developing compassion towards self and others. Early development of the approach was based on clinical observations that people high in shame and self-criticism often struggle to *feel* and internalise the alternative perspectives and modified beliefs developed in therapy, thus representing a serious barrier to therapeutic progress (Gilbert, 2010b, p. 7). Gilbert (2010b) notes that these individuals often come from backgrounds characterised by abuse, lack of affection and attachment difficulties (Andrews, 1998; Sandquist, Grenyer, & Caputi, 2009; Schore, 1998).

The foundations of CFT appear particularly well suited to PWLD. Attachment issues are common in PWLD due to factors such as parental stress, the challenges of providing effective parenting to a child with different needs, impairments in the cognitive skills needed for positive attachment interactions, and institutionalised care (Janssen et al., 2002). Children with LD have been found to have lower attachment security and emotion-regulation skills than those without LD and the interaction between these two factors contributes to difficulties with social information processing (Bauminger & Kimhi-Kind, 2008). Indeed, PWLD frequently lack good quality social and emotional support and relationships, even when accessing a number of social activities (Forrester-Jones et al., 2006; Lippold & Burns, 2009).

Additionally, it is proposed that self-criticism is more likely to occur in people who are sensitive to criticism from others, and that this sensitivity originates from negative social experiences (Gilbert & Procter, 2006). PWLD may be more likely to experience shame and self-criticism by virtue of negative social experiences such as interpersonal trauma and abuse, coupled with fewer coping skills than the general population (Hughes et al., 2012; Jones et al., 2012; van Nijnatten & Heestermans, 2010; Westcott & Jones, 1999). Research has found that PWLD are more likely to believe and be distressed by criticism than non-disabled peers (Esdale, Jahoda, & Pert, 2015) and PWLD remain some of the most stigmatised individuals in society (Thomas, 2000). Stigma in PWLD has been associated with negative evaluative beliefs about the self (Dagnan & Waring, 2004),

negative social comparisons (Paterson, McKenzie, & Lindsay, 2011) and poor psychological health (Ali, King, Strydom, & Hassiotis, 2015). Idusohan-Moizer and colleagues (2015) argue that PWLD often see themselves as vulnerable and rejected by others (external shame), and less able to function compared to others and therefore faulty or bad (internal shame). They argue that supporting PWLD to cultivate self-compassion can help them to develop a healthier relationship with themselves and their environment, easing the suffering associated with self-criticism and painful experiences.

### Affect Regulation Systems

CFT posits that there are at least three emotion-regulation systems: the threat (self-protection) system, the drive (resource-seeking/excitement) system, and the soothing (contentment/safeness) system. For the purposes of clinical utility and ease of understanding, the description of these systems and how they interact is presented in a simplified way (Figure 1.1) although it is acknowledged that the neurobiological underpinnings of these systems is complicated (Gilbert, 2014). Lee gives an overview of the systems that offers a detailed yet accessible way to describe them to service-users (Lee, 2012, pp. 23-42).



*Figure 1.1. Three Types of Affect Regulation System. From Gilbert (2009b) with kind permission from Constable Robinson*

The threat system detects threats quickly and instigates bursts of feeling that compel us to act in a way that protects us. A combination of genes and learning determine sensitivity and response to threat stimuli (Gilbert, 2009a). Difficulties can arise when the threat system is over-activated and responds to stimuli in an unhelpful way, for example to



a non-threatening stimulus or a response that is out-of-proportion to the threat. The drive system functions to create positive feelings that motivate us to seek out rewards, such as food, sex, friendship and shelter. However, our drive-system can become over-stimulated or ‘demanding’, which when blocked triggers the ‘threat system’ and associated emotional responses of anxiety or anger (Gilbert, 2009a). The soothing system provides a sense of contentment, well-being and connection. This system is linked to opiates, particularly oxytocin, which promote feelings of attachment and safety (Gilbert, 2015). It is through this system that we are able to provide and receive soothing and care, thereby promoting social affiliation. The soothing system can interact with the threat and drive systems to help regulate emotional responses to perceived threats and failures. Problems occur when this system is under-developed, meaning that the individual has limited resources to regulate threat- and drive-system processes and to feel connected and safe with themselves and others (Gilbert, 2009a).

CFT posits that all three of these systems are essential to our survival and we function at our optimum when they are balanced, but distress is caused when they become unbalanced. Imbalance can happen for a number of reasons but over-stimulation or heightened sensitivity of the threat and/or drive systems is common for those people who are high in shame and self-criticism (Gilbert, 2009a). CFT suggests that this is due to a limited ability to access the soothing system, often because of under-stimulation of this system in early life and the associated difficulties with attachment (Mikulincer & Shaver, 2007).

### **Applicability of CFT to Trauma**

Lee (2012) proposes CFT as a valuable approach for addressing trauma-related distress by strengthening the soothing system and, in turn, regulating the over-sensitised threat system. One aim of CFT is to facilitate engagement with, rather than avoidance of, painful experiences by developing an inner compassionate self (Gilbert, 2010a). This is particularly relevant in the context of PTSD, where efforts to avoid engaging with trauma memories inadvertently reinforce and maintain the symptoms (Ehlers & Clark, 2000). Perhaps most importantly, many people with PTSD experience high levels of shame (Harman & Lee, 2010), which is hypothesised to play an important role in the creation and maintenance of the current sense of threat associated with PTSD (Budden, 2009; Ehlers & Clark, 2000; Harman & Lee, 2010; Lee, Scragg, & Turner, 2001; Taylor, 2015). Traumatic experiences often provoke shame as people see themselves as damaged or contaminated by

the trauma in some way (Lee, 2012, p. 65). Additionally, prior experiences can increase the chances of shame and self-criticism developing. For example, those who have experienced previous traumas, bullying or rejection, or inadequate soothing from their care-givers as a child may assimilate the trauma as confirming their negative views of themselves (Ehlers & Clark, 2000; Lee, 2012). The prominence of such adversity amongst PWLD significantly heightens the probability of shame and self-criticism, thereby highlighting the applicability of CFT to this population to help cultivate compassionate resilience in the face of trauma.

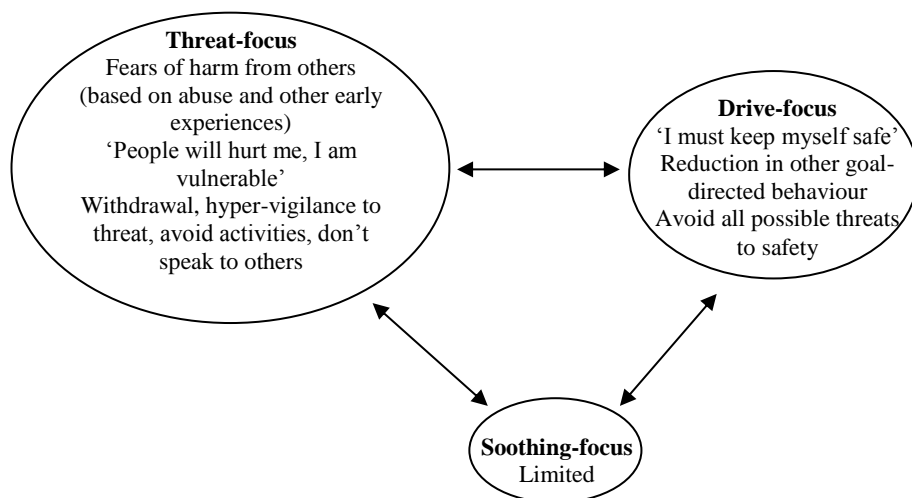
Furthermore, the increased likelihood of attachment difficulties and poor quality social networks mean that PWLD may be less able to trust or talk to others to help them make sense of and manage traumatic events (Mitchell, Clegg, & Furniss, 2006). Research has found that youths with LD have higher rates of PTSD than peers exposed to the same trauma, and that this variance in PTSD can be largely explained by previous exposure to threatening events and having an insecure attachment style (Finzi-Dottan, Dekel, Lavi, & Su'ali, 2006). The authors suggested that insecure attachments damage self-regulation, thus intensifying distress and increasing the likelihood of PTSD. CFT is particularly well placed to address these difficulties given its basis in attachment theory and social psychology, with a focus on improving affiliation, emotion-regulation and sense-of-safety.

### **Initial Stages: Psycho-education, Assessment and Formulation**

CFT is grounded in a philosophy and recognition that, “much of what goes on in our minds is *not of our design and is therefore not our fault*” [italics in original] (Gilbert, 2010b, pp. 61-62). Crucially, this de-shaming, non-fault position is coupled with the recognition that we each have the *responsibility* to approach and manage the unhelpful patterns inherent in our ‘tricky’ brains. This may be particularly powerful for PWLD who often blame themselves for being different and feel disempowered to be effective agents in their own lives. CFT is focused on developing an inner ‘compassionate self’ to help motivate people to engage in valued actions and respond to setbacks in a non-judgemental and constructive way (Gilbert, 2010b).

An initial formulation might involve asking a client to draw out the three affect-regulation systems (or ‘three circles’) with their size depicting how developed they are in relation to each other (Figure 1.2). A simplified formulation could be used with PWLD, for example using a small ‘kind circle’ and a large ‘scared circle’ with the focus of therapy

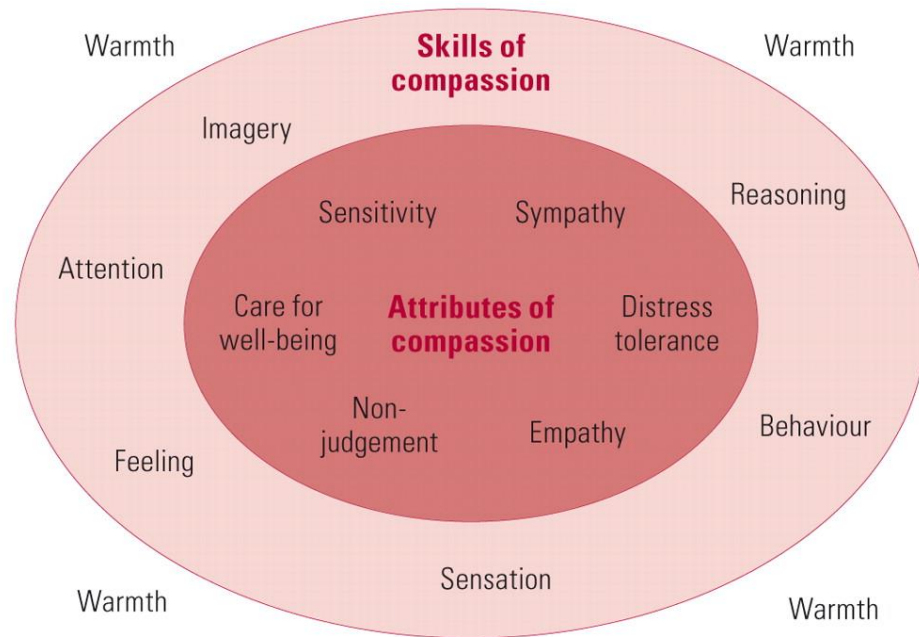
each week being on making the ‘kind circle’ bigger. More complex formulations can be used to develop a richer description (see Gilbert, 2010a).



*Figure 1.2. CFT 'Three Circles' Formulation Example*

## Intervention

CFT is a multimodal therapy that can be used as an intervention on its own or as an adjunct to other approaches. Many of the therapeutic techniques build upon those in other evidence-based therapies such as CBT (e.g. guided discovery), but with the distinctive emphasis on activating the affiliative soothing system to cultivate a more compassionate orientation to self, others and the world. CFT distinguishes between the attributes required to engage with situations compassionately, and the skills needed to develop and enhance compassion motivation (see Figure 1.3 and Gilbert, 2009a). CFT emphasises values-based actions that promote self-growth, rather than threat-based actions such as experiential avoidance. In this sense, CFT seeks to balance all three affect-regulation systems by mobilising the capacity of the soothing system to regulate perceptions of threat and threat-based drive (Gilbert, 2010b, p. 113).



*Figure 1.3. Skills and Attributes of Compassion. From Gilbert (2009b) with kind permission from Constable Robinson*

Compassionate imagery features prominently and is used to help develop and deepen thoughts, emotions and physiological responses associated with compassion. Compassionate imagery and meditation have been shown to bolster immune function and stimulate areas of the prefrontal cortex linked to empathy, soothing and well-being (Longe et al., 2010; Lutz, Brefczynski-Lewis, Johnstone, & Davidson, 2008; Pace et al., 2009). Other common techniques in CFT include soothing rhythm breathing, mindfulness, embodiment and exploration of the different ‘selves’ (e.g. wise/compassionate/kind-self versus angry/anxious/critical-self), compassionate chair work, compassionate reframing, compassionate imagery re-scripting, keeping a positive log, mentalising and compassionate letter writing (Gilbert, 2010b).

These skills-based approaches are amenable to being modified to suit the individual’s developmental level, making them particularly well-suited to PWLD. Less cognitively demanding elements, such as practising soothing breathing, using compassionate objects for grounding (including soothing smells and textures), creating art work that conveys compassion or helps to express other emotions, and simple mindfulness-of-an-object exercises could be used where an individual does not have the capacity to engage with more complex ideas. Additional exploration of compassion, potentially using

art work, enactment, chair-work, role-play, exploration of different selves, and non-verbal ‘acting as if’ could be useful to support the activation of the soothing system in PWLD.

In the case of trauma, the development of compassion-focused skills and resilience can serve as the foundation to focus this compassion specifically on PTSD experiences (Lee, 2012). Again, for PWLD techniques may need to be modified for the client’s developmental level. For example, by keeping a log of positive moments, bringing to mind the reassurance of a ‘kind best-friend’, or practising a series of positive self-statements with support from staff. Simple soothing breathing and compassion-focused imagery and writing or art exercises might help an individual to gently approach and work through trauma memories and flashbacks. In this way, CFT techniques could help PWLD to reclaim a sense of self and resolve past traumas by learning to activate an under-developed soothing system. Moreover, the collaborative skills-based approach seems likely to be experienced as empowering, nurturing and optimistic by PWLD, especially when set against the background context of stigma, social isolation and frequently traumatic life events.

## **Evidence**

The use of CFT with clinical populations has been growing in popularity in recent years in line with findings from a meta-analysis demonstrating a large effect size ( $r = -0.54$ ) between compassion and psychopathology, with higher levels of compassion being associated with lower levels of psychopathology (MacBeth & Gumley, 2012). A recent systematic review found CFT to be better than no treatment and as effective as treatment-as-usual (TAU) in addressing a range of clinical and non-clinical health and mental-health issues (Leaviss & Uttley, 2015). Self-compassion has been found to protect against PTSD symptomology after trauma-exposure (Hiraoka et al., 2015; Scoglio et al., 2015; Zeller, Yuval, Nitzan-Assayag, & Bernstein, 2015), mediated by emotion-dysregulation (Scoglio et al., 2015) and behavioural avoidance (Thompson & Waltz, 2008). Case-studies have demonstrated positive outcomes using CFT plus CBT or EMDR (Beaumont & Hollins-Martin, 2013; Bowyer, Wallis, & Lee, 2014; Kennedy, 2014), and controlled trials have found CFT to be as effective as CBT at reducing trauma-related distress (Beaumont, Galpin, & Jenkins, 2012; Held & Owens, 2015).

## **The Case for CFT with PWLD**

In light of the likely impact of adverse life events, attachment difficulties, and negative self-evaluation in the development and maintenance of trauma-reactions in PWLD, it is argued here that CFT merits investigation as an approach for addressing traumatic distress in this population. The adaptability of CFT to differing developmental levels – allied to increasingly powerful evidence supporting the clinical effectiveness of CFT for a range of psychological and emotional difficulties in the general population (Gilbert, 2015) – further supports the contention that CFT could make a valuable contribution to improving the wellbeing and mental health of PWLD.

### **Evidence from Mindfulness Interventions**

Mindful compassion skills represent a core foundation of CFT, and there is emerging evidence that adapted mindfulness exercises are both accessible and beneficial interventions for a range of concerns in PWLD (Croom, 2016). Some researchers have proposed that self-compassion may be a mechanism by which mindfulness improves wellbeing (Baer, 2010; Hölzel et al., 2011). Indeed, self-compassion has been found to mediate the relationship between mindfulness-based interventions and a number of beneficial clinical outcomes including reductions in depression and stress, and increases in positive emotions (Chiesa, Anselmi, & Serretti, 2014). A 9-week mindfulness-based cognitive-therapy group for PWLD was found to significantly increase self-compassion from pre- to post-group, and all participants reported enjoying the sessions that specifically focused on compassion (Idusohan-Moizer et al., 2015).

### **CFT with Staff Teams**

It is vital that services heighten their awareness and responsiveness in challenging organisational cultures that foster abuse or disrespect of PWLD and thereby inhibit compassionate care. Given the prevalence of traumatic experiences amongst PWLD, services must also be alert to the possibility of re-traumatisation in healthcare settings and seek to adopt trauma-informed care (Keesler, 2014). Thus, the role of compassion at the level of service and organisational culture is every bit as important as in the context of individual interventions.

Cole-King & Gilbert (2014) discuss how healthcare systems that facilitate compassion can lead to better patient experiences and clinical outcomes, as well as higher job satisfaction for staff. They also note a number of barriers for services adopting a

culture of compassionate care and suggest that highlighting and addressing these is important. A number of core themes to promote and facilitate compassionate care have been identified, including: high quality patient care as the central focus of the organisation; compassionate behaviour from organisation towards staff (including training); creating stable staff groups with the right values; fostering affiliation within and between teams; and good communication (Royal College of Psychiatrists, 2015). In the case of trauma in PWLD, a number of additional important elements deserve attention, including: education and awareness about trauma; interacting with service-users in a way that creates a sense-of-safety and boundaries; normalising and understanding responses to trauma; and encouraging staff to develop reflectivity around their own stance on trauma and PWLD so that they can be supervised accordingly and minimise the risk of vicarious trauma (Grech, 2014).

Compassion is best understood as a ‘bottom-up’ process in which individual clinicians might take opportunities to introduce, share and deepen team and service awareness of the philosophy, principles and skills of CFT. For instance, team meetings could be used to introduce compassion-focused approaches and skills. This might usefully include creating collaborative compassion-focused formulations, intervention plans and goals. Emphasising the affiliative and relational elements of CFT should help to create positive attachment experiences for both service-users and staff. Shea, Wynyard and Lionis (2014) provide a helpful discussion of opportunities to develop and embed compassion-focused practices in healthcare services.

### **Case Examples**

One of the authors (MC) has used CFT with PWLD in the context of a range of presentations, including those hypothesised to be linked to trauma. An overview of work with three individuals is provided to illustrate the potential utility of CFT in complex cases where issues have persisted despite previous psychological and pharmacological input. Two individuals had diagnoses of autism spectrum disorders (ASDs) and the other individual had a suspected ASD (see Table 1.1). In all three cases the presenting problem on the referral did not include reference to trauma, however trauma was identified in the course of information gathering and assessment and included in formulations. Level of LD was determined as part of an eligibility assessment process to access the service. Verbal and written consent was obtained from the three service-users and their carers for these cases to be written up anonymously and submitted for publication.

Table 1.1

*Overview of Demographics and Trauma-related Information for Three Case Examples*

Demographics	Presenting Problem	Potential Traumas (key events in bold type)	Trauma-related Symptoms
<p><u>X</u>: Male, 50s, White British</p> <p>Moderate LD, ASD, living in a residential setting with 24hour care</p>	<p>Diagnoses of ASD, OCD and depression (anti-depressants prescribed). Support sought for managing aggression towards self, others and property, as well as self-harming behaviours (low risk).</p>	<ul style="list-style-type: none"> <li>• strategies used to manage X's behaviour in early life included excessive punishment from parents</li> <li>• <b>physical and emotional abuse from father</b></li> <li>• institutionalisation from a young age</li> <li>• moving residence a number of times with little preparation, including loss of a relationship</li> </ul>	<ul style="list-style-type: none"> <li>• self-harm, anger and aggression</li> <li>• shouting at self in the mirror</li> <li>• repeating words suspected to have been heard from abuser</li> <li>• changes in behaviour after home visits including tearfulness, withdrawal from usually enjoyed activities, jumpiness and sleep problems</li> </ul>
<p><u>Y</u>: Female, 40s, Black Caribbean</p> <p>Moderate LD, living with full-time professional carers</p>	<p>Diagnoses of ASD and depression (anti-depressants prescribed). Historical and recent issues with severe aggression towards self and others, including serious self-harm, and behaviour that challenged others. Physical aggression had not been an issue for approximately 6 months. Support sought for extreme hoarding behaviours (moderate-high risk) and verbal aggression.</p>	<ul style="list-style-type: none"> <li>• family unable to manage Y's needs at a young age resulting in frequent, distressing altercations</li> <li>• institutionalisation from a young age for &gt;25 years</li> <li>• <b>alleged historical racial and physical abuse from care staff and other residents</b></li> <li>• witnessing domestic violence towards sister</li> <li>• moving residence a number of times with little preparation</li> <li>• a number of hospitalisations for physical health problems</li> </ul>	<ul style="list-style-type: none"> <li>• self-harm, anger, aggression and low mood</li> <li>• verbalising memories of abuse, often fantastical in nature, consistently throughout the day</li> <li>• very frequent outbursts of abusive comments towards self and others</li> <li>• rejecting care from others and sabotaging usually well-liked activities</li> <li>• hoarding behaviour formulated partly as a response to trauma – need for physical barriers plus sense of comfort, safety and consistency in self-identity and relationship to others</li> <li>• isolating self from others, difficulties with trust</li> </ul>



<p><u>Z</u>: Male, 70s, White British</p> <p>Mild LD, living in the community with daily care provision</p>	<p>Diagnoses of severe GAD and schizophrenia (both medicated). Input from several psychologists and other healthcare professionals in the past with no long-term improvements in anxiety. Support sought for anxiety to augment attempts to reduce medication</p>	<ul style="list-style-type: none"> <li>• early family issues</li> <li>• distressing psychotic delusions</li> <li>• historical side-effects from medications that were not addressed or explained</li> <li>• <b>arrests – being sectioned</b></li> <li>• institutionalised care from a young age for &gt;30 years</li> <li>• <b>discovering a loved one’s dead body</b></li> <li>• moving residence a number of times with little preparation, including loss of a best friend</li> <li>• moving from 24 hour residential care to supported independence</li> </ul>	<ul style="list-style-type: none"> <li>• poor emotion regulation (very fast escalation)</li> <li>• extreme hypervigilance to threat and continuous ‘jumpiness’</li> <li>• intense anxiety reactions to police sirens and doctors</li> <li>• ‘zoning out’ when unable to distract from distress (dissociation)</li> <li>• shouting a loved one’s name (despite their death occurring &gt;35 years ago)</li> <li>• avoidance of discussing trauma events in any detail or visiting areas associated with traumas</li> <li>• frequent outbursts of crying</li> </ul>
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## Intervention

Simplified socialisation to the model was based around an explanation that, “people feel best when they have balance in their feelings, but often our sad, worried or scared feelings are very big. The sessions will aim to make the calm, kind, happy and strong feelings bigger”. Formulations were completed with X and Z comprising of the simplified two circle process described above. Whilst X and Z understood that the ‘kind/calm’ circle needed to be bigger to help make the scared/angry circle smaller, it was less clear that they always understood the circles as representing processes inside of themselves. Y did not engage with attempts to develop a formulation. Lots of visual information was included with each of the techniques that were introduced, normally in the form of instruction sheets with large pictures on one side and simple written instructions on the back for carers. Homework tasks each week were to practice techniques daily with carers, marking this on a visual diary.

A range of CFT intervention techniques (Table 1.2) were used depending on what was accessible and acceptable to the client. Interestingly, all three individuals engaged particularly well with a simple smiling-in-the-mirror exercise. This involved clients standing in front of the mirror, either alone or with a carer, and watching themselves smile for approximately 30 seconds or more. It was evident that they became visibly happier both during and after the exercise. Carers noted that as practise continued, they were able to encourage the individual to use this technique when they were agitated and it would reduce or eliminate their distress. Compassionate facial expressions, including gentle smiling, are important components of CFT imagery exercises (Gilbert, 2009b). This technique involves physically altering the body to elicit positive affect, as well as being able to see, and therefore perhaps feel, the self being happy. By joining in, carers might well enhance the effectiveness of the exercise by creating a sense of affiliative connection, a central tenet of CFT.

Table 1.2

*Key CFT Techniques used with Case Examples*

CFT technique	Descriptor
Soothing rhythm breathing	Practicing breathing at a calm, soothing pace – using deep belly breathing through the nose where possible. Further guidance at: <a href="https://www.youtube.com/watch?v=TtZqRLcG48g">https://www.youtube.com/watch?v=TtZqRLcG48g</a>

Progressive muscle relaxation	Tensing and then releasing key muscles in the body to improve ability to relax
Safety statements	Repeating statements such as “I am safe”, “I can ask for help” and “I am loveable” as well as more classic CBT now vs. then statements such as “I am now 54, I was 24 when the event happened”
“It’s not my fault” and “there are things that can help”	Encouraging use of the statement “it’s not my fault” when service-users are engaging in self-critical self-talk. Encouraging engagement in helpful activities appropriate to ability level, for example asking staff for support or using something from the grounding materials
Imagery	Safe-place imagery, compassionate colour imagery and compassionate being imagery were used to activate the soothing system
Drawing ‘calm’ and ‘scared/angry/sad’	Drawing how different feeling states might look in order to externalise and better understand feelings. Exploring how these feelings might impact the body and marking this on drawings of a body outline
Using pictures of feeling states	Training service-users to identify the emotion being expressed in a given photo (e.g. happy; sad; angry; calm) and using these to communicate with staff about their mood – some service-users had ‘mood charts’ where this was recorded
Positive self-statements	Statements about positive characteristics, such as ‘I am friendly’, to be repeated by the service-user. Carers and staff can be asked to generate these statements in cases where this may help other-relating or where service-users struggle to identify anything positive about themselves
Inner best friend	Thinking about how a best friend would talk to you and support you – trying to take this attitude towards yourself
Positive/soothing activity scheduling	Ensuring meaningful activities that the service-user enjoys or that help the service-user to feel soothed are included in daily planning
Positive logging	Carers log positive events and moments from the day that the service-user has enjoyed, using input from the service-user where possible. This is then read to the service-user at the end of each day
Compassionate grounding objects (or ‘compassionate first aid kit’)	Use of objects such as a textured soft cloth, coloured glass stones, small cuddly toys, strongly flavoured sweets, ‘noisy’ material like sweet wrappers and lavender oil for smelling to provide sensory grounding to the here and now. The use of these are particularly encouraged at times when flashbacks or memories are coming up or when distress levels are elevating

Relaxing music	Choosing music that the service-user finds relaxing and setting aside time to listen to this
Mindfulness of an object	Exploring an object using all five senses, noticing how it feels to be curious but non-judgemental
Encouraging spending time with preferred others	Facilitating interpersonal contact and connection
Positive feedback	Staff and carers encouraged to praise service-users when appropriate
Remembering traumas in past tense	Talking over trauma memories whilst using grounding techniques to minimize distress escalation. Talking in the past tense and beginning with naming the event, then progressing to exploring details of the event and any feelings and thoughts that come up. Only for use when the service-user is aware that reliving may cause distress in the short term (but could help to feel better in the long term) – seek consent and develop grounding skills first
Memory re-scripting/alternative imagery	Creating alternative endings for memories or preferred outcomes. For example, “my loved one is now in heaven”. Further exploring these with art work where this is acceptable to the service-user
Boundary setting	Ensuring clear boundaries are in place and acknowledged by all staff members to help provide a predictable environment (e.g. using timetables, having clear rules and consequences)
Session countdown	Having a clear countdown through the last five sessions to help service-users feel aware of the ending of the therapeutic relationship. To give service-users experience of a positive and planned ending
Staff meetings around compassion	These meetings can take various forms. In these case examples they included: large network meetings where timelines of the service-user’s life were shared to encourage compassionate understanding of the presenting difficulties; inviting service-users to team meetings to reflect on CFT input and to empower the service-user; multi-agency meetings to encourage a joined-up, consistent approach to service delivery for a service-user. The concept of compassion and its relevance to the service-user was explored. Brief training in maintaining CFT techniques with the service-users was given and resources were shared
Sessions with family members	Compassionate meetings taking a non-judgemental stance to understand family members’ views and experiences of the service-user. Attempting to share CFT formulations and ideas for continuing compassionate approaches at home

## **Outcomes**

Staff reported (verbal feedback and a pre- and post-therapy outcome measure) that X became visibly happier, smiling, making eye-contact and walking more upright. X began to request that staff smiled in the mirror with him at various times each day and reportedly found other compassionate exercises easier and more enjoyable the more he practised them. All trauma-related symptoms resolved entirely apart from aggression to objects, which reduced markedly but still occurred at a lower level when X was feeling frustrated about something that had occurred that day. These improvements were still being maintained four months after the sessions ended.

Y appeared to flourish when expectations of her were clarified and boundaries were firm yet flexible, in-line with CFT's focus on developing secure attachments. Y eventually began to trust the therapist and by the end of three months working together had managed to clear hoarded objects from her room to a safe level. Verbalisations of trauma memories had reduced to only a few times per week. Expressions of verbal aggression to others did not change (staff at her day centre reported that they may have increased) but verbal aggression towards herself had stopped. Furthermore, both staff and Y's live-in carer reported increased confidence in ways to support Y moving forwards. Progress was maintained at one month follow-up.

Z's level of anxiety remained high but flashbacks were substantially less frequent, tearfulness reduced and 'zoning out' was no longer observed. The deceased loved one's name was called out less frequently, and without visible distress. Z could now talk about trauma events in more detail, although still displayed jumpiness and an apparent sense that something bad was about to happen. Z did not consent to a more detailed exploration of the trauma events and it may be that trauma re-processing was necessary to see more significant improvements. Staff felt that whilst Z's anxiety remained very elevated, they now had skills to manage anxiety and intrusions in the short-term and trauma-related symptoms were much diminished.

## **Reflections**

The effectiveness of CFT is contingent upon regular practice to activate the soothing affect system. This is especially pertinent for PWLD who are likely to require repetition of information and skills before they can carry them out independently. It appeared that X and Y struggled to retain information, making a skills-based and 'embodied' approach more accessible. In all cases it was imperative to work alongside

carers and staff teams to encourage a broader compassion-focused understanding and approach to care. Staff and carers also offered expert information about clients, facilitated communication with clients and were well placed to ensure CFT practice took place. Where safety issues were present, such as self-harm and abuse, it was important that these were identified and addressed expediently.

These case examples provide preliminary evidence that elements of CFT can be used in adapted form with a range of trauma-presentations and intellectual abilities with positive outcomes. It is likely that further sessions would have been beneficial for Z, and indeed the care team planned to continue implementing CFT techniques. The cases give a snapshot of how compassionate techniques can be applied with PWLD and within the wider service system. Whilst case study findings cannot be generalised, the outcomes highlight the potential utility of CFT for PWLD who are experiencing trauma-related distress.

### **Potential barriers**

Barriers to working successfully with CFT can include negative perceptions of compassion as weak, not to be trusted, or something that is not deserved (e.g. Pauley & Pherson, 2010). Additionally, for people who have experienced abusive backgrounds – unfortunately familiar amongst PWLD – the experience of compassion can ignite feelings of sadness and grief, or even aversive and frightening physical reactions (Gilbert, McEwan, Catarino, & Baião, 2014; Gilbert et al., 2012; van der Kolk, 2014). Notwithstanding these difficulties, Gilbert (2009a) argues that people from socially impoverished and difficult backgrounds may stand to gain the most from compassion-focused skills and therapy.

Many of the compassion-focused interventions are skills-based and behavioural, thereby circumventing the need for a deeper intellectual engagement with the therapy, which might otherwise represent an obstacle for many PWLD. For instance, simple soothing rhythm breathing and compassionate colour or place imagery can activate the soothing system without any requirement for more challenging cognitive techniques. As discussed above, CFT can be readily adapted for different developmental levels. Lawrence and Lee (2014) offer a model, based on clinical experience with CFT and qualitative feedback, which proposes that the therapeutic relationship and the emotional experience of therapy can help move clients from being scared of self-compassion to accepting self-

compassion. Establishing a secure therapeutic alliance creates the context for developing capacities to give and receive compassion, rather than relying on cognitive abilities.

Finally, one might question the value of cultivating self-compassion within individuals in the absence of meaningful change in the wider system. It is clear that systemic factors contribute markedly to mental health problems in PWLD, and arguably efforts might be better spent in addressing such issues, as well as the attitude of society more broadly towards PWLD. Whilst these are important considerations, the existing prevalence of trauma in PWLD compels the development of more effective interventions for alleviating psychological distress and improving quality of life. The cultivation of compassion to promote healthy affect regulation, a positive sense-of-self, a sense of safety, and connection to others can be one way that PWLD are facilitated to manage the effects of trauma. The critical work of changing society's perception of PWLD at the macro level, and considering the individual's systemic context at the micro level, can take place alongside individual therapeutic interventions.

### **Future Directions**

The lack of evidence for effective interventions for mental health problems in PWLD urges further research exploring potential treatments and extending the existing evidence base. This is particularly relevant for PWLD experiencing traumatic stress reactions given the prevalence and impact of trauma in this population. The theoretical underpinnings of CFT – especially its focus on attachment, self-concept, collaboration and empowerment – underpin its potential utility for improving psychological wellbeing amongst PWLD. The transdiagnostic nature of CFT and its complementarity with other therapeutic approaches offers valuable flexibility and practical application in multidisciplinary teams. There is an emerging evidence base for a diverse range of therapeutic models within the LD literature (Beail, 2016) and CFT appears to be an obvious area for further exploration.

Given these considerations, research exploring the use of CFT with PWLD, especially those who have experienced trauma, is indicated. Studies may usefully explore whether CFT improves the efficacy of TF-CBT or EMDR as well as investigating CFT as a standalone treatment. Controlled trials may be the ultimate goal for establishing the efficacy of CFT at improving wellbeing and reducing trauma-related symptoms in PWLD, however case designs are a useful starting point given the heterogenous population. Case designs allow for a more detailed investigation of qualitative elements and fluctuations in

quantitative measures, facilitating exploration of the specific processes at play as well as any interacting, moderating or mediating relationships between variables. Important lines of enquiry include the influence of developmental level and whether there are specific ‘ingredients’ of CFT that are more or less effective in this population, such as the ‘smiling-in-the-mirror’ technique outlined in this paper.

Services supporting PWLD should seek to deliver care in a way that promotes safety, trust, choice, collaboration and empowerment to reduce the potential for further distress or traumatisation. Compassion-focused therapy encourages this approach, with a focus on strengths, skills and affiliation at the individual, professional and organisational level. Culture shifts can be driven powerfully through a bottom-up process grounded in a compassionate philosophy at individual, team and service levels. Managers would ideally recognise the value of instilling a compassionate culture in their teams, in order that the broader benefits are realised throughout the organisation and its interaction with the wider healthcare system. Accordingly, cultivating compassion-focused therapies can be conceptualised as one step towards redressing the disempowered position of PWLD in society and reducing the potential for iatrogenesis and abuse from care staff.

### **Conclusions**

This conceptual review has explored the potential applicability of CFT for trauma in PWLD, positioning the theoretical roots and inherent flexibility of the approach as particularly aligned with the supportive needs of PWLD.

### **Existing Literature**

The literature around trauma in PWLD highlights the greater prevalence of exposure to trauma and, unsurprisingly, the greater incidence of clinically significant responses to trauma than the general population. Despite this, the literature into interventions for addressing trauma in PWLD is limited to case study and case series designs and no official guidelines exist for best-practice in addressing trauma-reactions in PWLD (e.g. Mevissen & de Jongh, 2010; Mevissen, Didden & de Jongh, 2016). Although EMDR and TF-CFT are promising approaches in this population, they may not be suitable for everyone and existing research lacks rigour. It is proposed that the prevalence and impact of trauma on the lives of PWLD, as well as the limited evidence base for treating trauma in PWLD, highlights the need for more research in this area.



## **Key Points from this Review**

Given the focus of CFT on improving emotion regulation, encouraging social affiliation, and cultivating resilience and self-soothing in the face of adversity, it has been argued that the approach could add therapeutic value in the context of trauma in PWLD. This review has highlighted ways in which CFT aligns with the experiences and needs of PWLD and how the approach might be modified for differing ability levels. Specifically, CFT could: augment established trauma therapies such as CBT and EMDR; address trauma-reactions as a therapeutic framework in its own right; and encourage staff teams to deepen their engagement with clients from a compassion-focused perspective. Clinical and empirical evidence for the efficacy of CFT in the general population and more specifically for trauma has been developing rapidly in recent years.

## **Strengths and Limitations**

As a conceptual review, this paper suffers from a lack of evidence to demonstrate that CFT is beneficial for PWLD who have experienced trauma. The paper is based largely on theory, non-intervention studies, evidence from other approaches (e.g. mindfulness), anecdotal evidence from clinical practice, and evidence from populations without LD. It was developed based on observations that the theoretical underpinnings of CFT are well aligned to the experiences of PWLD, and clinical experience of successfully being able to adapt this approach to support PWLD who have a history of trauma. However, CFT has not been researched as an intervention for PWLD and as such it remains to be seen if the assertions here are substantiated.

However, CFT in the general population has a burgeoning evidence base, including specifically as a framework for trauma interventions. The authors' feel strongly that the evidence-base for PWLD should be developed in parallel with interventions for the general population rather than being an 'after-thought', as has been the case too often in the past. Additionally, CFT can be used as a specific framework from which to deliver CBT, which has a relatively good evidence for addressing psychological distress in PWLD (Beail, 2016). This, as well as the evidence from mindfulness interventions, adds credibility to CFT as an appropriate and potentially beneficial approach for addressing trauma in PWLD.

Strengths of this review include its focus on promoting the needs of PWLD and encouraging a scientist-practitioner approach. It is likely that many clinicians on the ground are using CFT in various formats to work with PWLD. This paper suggests that this is a valuable endeavour, but needs to be formally assessed and disseminated so that the

field can develop an evidence base and guidelines about best practice can be developed. This paper also draws attention to the importance of trauma in the lives of PWLD and therefore the importance of more, and more rigorous, research in this area; further exploration of EMDR, TF-CFT, and more novel approaches such as CFT is clearly needed.

### **Next Steps**

It is suggested that further research employing single case or case series methodology represents an optimal next step to elucidate the potential of CFT for trauma (and more generally) in PWLD. Emerging findings might then provide the foundation for controlled trials and the development of compassion-focused treatment packages and resources for clinicians to offer to this population in need.

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**Service Improvement Project: How Stroke Patients and  
Carers Experience an Early Supported Discharge  
Service: Service Improvement Driven by Service-User  
Perspectives**

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Please see Appendix B for instructions to authors and Appendix C for the front  
page of the published version.

## **Introduction**

Stroke is a major health problem in the UK with approximately 125, 000 people having a stroke every year (based on NICE, 2013). Mortality and morbidity rates are high, with stroke being the fourth most common cause of death and the leading cause of complex disability in the UK (Stroke Association, 2015). Evidence suggests that rehabilitation outcomes are improved with early support (Cumming et al., 2011; Stroke Unit Trialists' Collaboration, 2013), and that early stroke care is associated with potentially large hospital cost savings (Svendsen, Ehlers, Hundborg, Ingeman, & Johnsen, 2014).

## **Early Supported Discharge Services**

Early Supported Discharge (ESD) services were developed to provide intensive and specialist multi-disciplinary care for stroke patients at home. Clinical trials (Fearon, Langhorne, & Trialists, 2012; Langhorne et al., 2005) and effectiveness studies (Fisher et al., 2015) have found evidence-based ESD services to reduce hospital stay and result in equivalent or better outcomes for mild-moderate stroke survivors and their carers compared to conventional hospital-based or home-based care.

NICE guidelines recommend that ESD services should offer: continued inter-disciplinary communication; an agreed health and social care plan before discharge from hospital; rehabilitation goal setting; provision of information (with a 6 week and 6 month review); assessment of, and when needed, provision of care for: cognitive functioning, emotional functioning, vision, swallowing, communication, and movement; at least 45 minutes of therapy 5 days per week for those capable; supporting self-care; promotion and facilitation of community activities, social identity and return to work; and information regarding how to access future support (NICE, 2013).

## **The Service**

The Bath and North East Somerset (BANES) ESD service is part of the Community Neuro and Stroke Service (CNSS), alongside the Planned Rehabilitation service. The service is needs-based and supports those with intensive rehabilitation needs, which in most cases refers to stroke patients as they transition from hospital back into their homes and their communities, but also covers other neurology patients with acute rehabilitation needs. The service is comprised of physiotherapists, speech and language therapists, occupational therapists, a health psychologist (supported by a clinical neuropsychologist), specialist stroke nurses, a counsellor and an embedded stroke co-

ordinator from the Stroke Association based in the same office, as well as administration support and management.

Previous qualitative evaluations of ESD services for stroke patients have identified carer support and training, provision and consistency of stroke-related information, emotional support, fostering hope, and transitions from ESD into future services to be areas of concern for both stroke patients and their carers (Cobley, Fisher, Chouliara, Kerr, & Walker, 2013; Taule, Strand, Skouen, & Råheim, 2015). Research with community stroke-support staff has highlighted that the psychological impact of stroke is a prevalent but often inadequately addressed area of concern for stroke survivors, and that further attention should be given to providing support and training to staff in this area (Morris, 2016). The BANES CNSS ESD service had not explored whether the concerns highlighted in previous research were also apparent in their service.

### **Aims of this Study**

This service improvement project was commissioned by the BANES CNSS ESD service team leader, Lisa Maendl, and team manager, Emma Caleb. Consultation with the commissioners highlighted that there was a need for service-user perspectives to be further explored to inform meaningful service evaluation and development. It was agreed that qualitative research would be conducted to explore patients' and carers' expectations, needs and experiences of the service. The main aims of this study were to: (1) evaluate the BANES CNSS ESD service from patient and carer perspectives; (2) specifically explore service-user satisfaction with regards to potential areas for improvement highlighted in previous literature; (3) use data from this evaluation, existing literature and staff views to inform recommendations on how to improve the service; and (4) to help implement these recommendations where appropriate.

In the rest of this paper the term 'service-users' will be used to describe both patients and carers, with 'patients' or 'carers' being used to refer solely to the named group.

## **Method**

### **Participants**

Participants were patients or carers who had been discharged from the service between one week and 6-months before the study took place. Inclusion criteria were that the patient had been seen after a stroke, that they had used the service for a minimum of a month and that they had received care from a minimum of two team members and for a



minimum of five sessions. Exclusion criteria were that the patient had suffered a sub-arachnoid haemorrhage, had another major neurological diagnosis, was receiving palliative care, had clinician rated severe cognitive or language deficits or had clinician rated lack of capacity to consent. In order to try and maximise the representativeness of the sample, patients with mild to moderate aphasia were included in recruitment. Carers were eligible if the patient they cared for met the inclusion criteria (carers of patients with severe cognitive or language deficits or who lacked capacity were also included), the carer was able to engage with the interview and they were not paid carers. Carers of patients who had died were not invited to take part in the study and carers of patients who were taking part in the study were not invited to take part to avoid over-representation of particular experiences. Please see Figure 2.1 for a flow diagram of study participation and Table 2.1 for a summary of key participant demographics; all participants were White British.

## **Procedure**

Potential participants were contacted by a known team member at the service and, if they were interested, the lead researcher would contact them to arrange a convenient time to meet and send out an information sheet. Face-to-face, semi-structured interviews took place between June and July 2015 at the participants' place of residence; these were between 25-50 minutes in duration. Interviews were audio recorded and brief field-notes were made. The audio recordings were later transcribed and anonymised before being deleted.

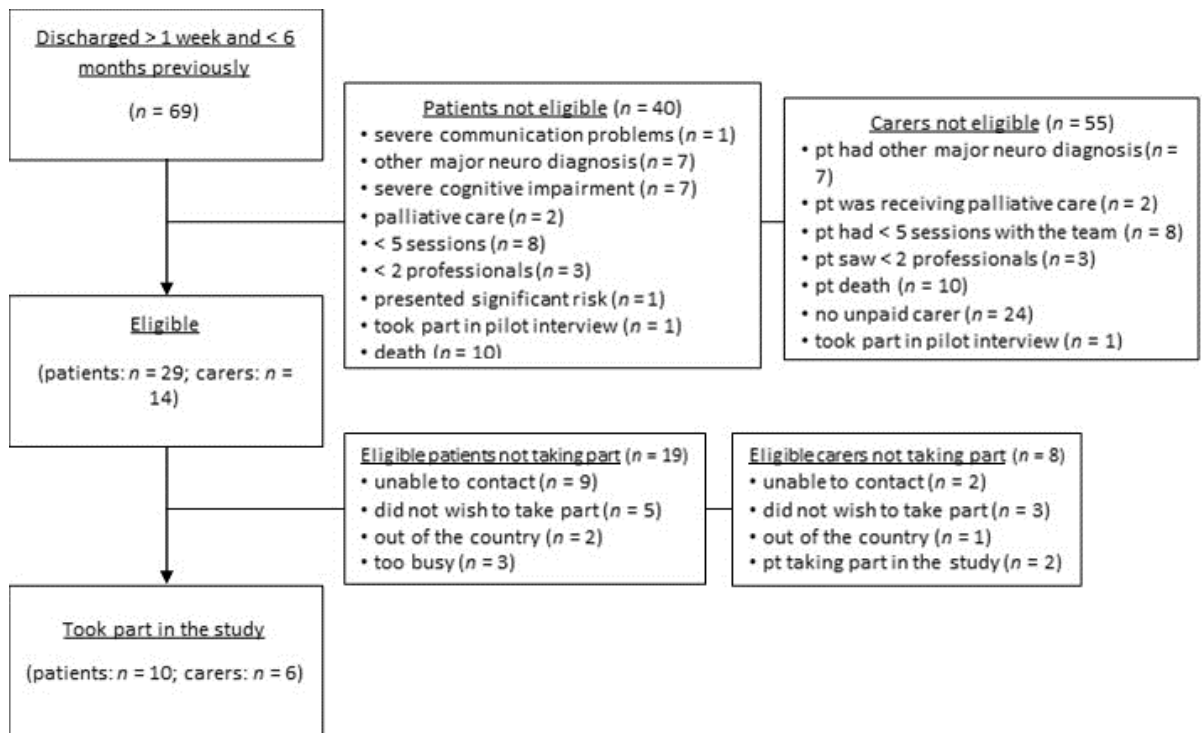


Figure 2.1. Flow Diagram of Study Participation. (Key: *pt* = *patient*)

## Interview Procedure

Meetings were held with the service to discuss which topics would be useful to cover. An initial draft interview-schedule was developed and then piloted with one patient and one carer. Their feedback was incorporated to develop the final interview schedule, which broadly covered the topics outlined in previous qualitative research into ESD services (Cobley et al., 2013; experiences of the ESD team, areas for improvement, support provided, changes in well-being, and impact on daily living). The questions were delivered in a flexible manner, depending on the interviewee's narrative, and any relevant topics that were raised were explored further.

Table 2.1

*Demographic Information for Patients and Carers*

<b>Id</b>	<b>M/ F</b>	<b>Age</b>	<b>Time since stroke (wks)</b>	<b>Time since discharge from ESD (wks)</b>	<b>Stroke severity (Rankin scale)</b>	<b>Patient cognitive problems</b>	<b>Patient communi- cation problems</b>	<b>Hours</b>	<b>No. of pros</b>	<b>Relation to patient</b>
C1	F	80s	33.3	9	5	Severe	Severe	124.4	4	Wife
C2	F	50s	31.3	4	4	Moderate	Moderate	304.8	4	Daughter
C3	F	70s	53.4	23	5	Severe	Severe	74.9	4	Wife
C4	M	60s	60.0	21	3	None	None	62.5	3	Husband
C5	F	60s	38.3	25	2	Severe	Mild	16.9	4	Daughter
C6	F	50s	39.6	11	5	Severe	Moderate	186.6	3	-in-law
P1	F	60s	56.0	22	3	Mild	Mild	70	3	Daughter
P2	F	90s	21.9	5	4	None	None	44.2	4	
P3	M	40s	28.7	23	2	None	Mild	7.1	4	
P4	M	60s	61.4	21	4	Mild-	Moderate-	86.9	4	
P5	M	80s	50.4	25	1	Moderate	Severe	11.9	3	
P6	M	70s	30.1	20	3	None	Mild	13	5	
P7	M	80s	39.9	25	3	Mild	Mild	54.3	3	
P8	F	50s	41.6	12	2	Mild	Mild	8.6	3	
P9	F	70s	43.6	7	4	Mild	Mild	233.7	4	
P10	M	70s	28.5	7	3	Mild	Mild	39.9	5	

*Note: Id = identification code; M/F = gender; wks = weeks; No. of pros = number of professionals involved in care; C = carer; P = patient*

**Analysis**

After the interviews had been transcribed, the carer and patient transcripts were analysed separately using the six-step thematic analysis process outlined by Braun and Clarke (2006). This involved the first author reading the transcripts several times to become familiar with the data and begin searching for meanings and patterns relevant to the research question. Initial codes were then marked and extracts collated before being explored for similarities in the ideas that were being conveyed. Codes that carried a similar meaning were combined to form themes, and these themes were investigated to check that they were coherent and valid. Any extracts or codes that contradicted or challenged a theme were collated and included within that theme for consideration. Themes that were based on highly inconsistent codes or did not have enough data to support them were discarded, and themes that were very similar were merged. The data-set was re-read at this stage to check that the resulting themes captured the essence of the interviews. These themes were then defined and organised, with sub-themes that had complimentary meanings being grouped to form super-ordinate themes (see Appendix D for some examples of the analysis process). Vivid citations were chosen to give lucid examples of

the main focus of each theme. A second researcher analysed the data in a less intensive, but similar way and made suggestions for how to define themes and refine the content at the later stages of this process. Opinions about key meanings and themes were very similar between the researchers.

The data was approached from a realist, inductive position, assuming that participants' accounts were accurate representations of their experience and that themes were being developed based on the content of the data and not on previous research. However, it is important to note that the researchers were familiar with previous research and it is impossible to be completely neutral to theory and previous findings.

## **Ethics**

The study was assessed and approved by the University of Bath Psychology Department Research Ethics Committee (ref: 15-114). The local NHS Research & Development (R&D) office judged the study to be a service evaluation and therefore not requiring R&D approval. All participants were given information sheets and consented to their anonymised data being used before taking part in the study. Participants were informed that they could withdraw from the study at any point. A sheet with contact details for support services was given to participants at the end of the interview as well as the opportunity to engage in a relaxing imagery practice.

## **Results**

Themes stemming from the data are reported separately for patients and carers. Please see Table 2.2 for a summary. Several of the themes perceived in the data were closely related, resulting in some overlap in which codes were deemed relevant for each theme.

Table 2.2

*Carer and Patient Themes*

	Theme	Sub-theme	Illustrative quotes
Carers	Transitions	Facilitating the move home	<p>...it was brilliant, particularly during the transition between hospital and her home, it really helped (carer 2)</p> <p>...it was all focused on having everything in place ready for her to come home (carer 4)</p>
		Well prepared endings	<p>...when they first discussed it with her it was at least a couple of months beforehand...I think it went down to twice a week or once a week...it was all done pretty well actually (carer 6)</p> <p>...it's an on-going as-and-when, sort of when they feel that that person needs to have another visit...that was very helpful, that we had that back-up (carer 4)</p> <p>...they done an extra two weeks...then they had a morning with the ones that are coming now...to give them an idea of what they do (carer 1)</p>
		Access to valuable information	<p>They were great, you know they took a great deal of time to explain who they were, what they did and brought the photographs of the team...we had written documentation with photographic representation of processes, which all changed as time went on and were updated (carer 6)</p> <p>Cos not having any experience of people with stroke it was um, a relief to have that back-up team there who could explain what was going on and, um, advise us so that we knew we were doing the right thing by [patient]; that was really what we needed (carer 5)</p>
	Knowledge sharing	Uncertainty about the future	<p>Time was going on and on and on, you know it was about 5 months and we didn't have a clear direction or idea of what was happening and where it was going to go (carer 2)</p> <p>...but we just think that now he's sort of stuck. There's no-body you know doing anything to make it any better...what else can we do...I'm anxious to try and get him going a bit more...we think we could have gone on learning some more things (carer 1)</p>

		<i>...it's not easy for them, from the point of view that everybody's stroke is different, and the effects of a stroke are so radically different between one person and another. They can't cover all bases (carer 4)</i>
	<i>Keeping the family informed</i>	<i>...we were included in the tuition and procedures...we could ask the same question over and over again and it was always answered...time was always taken (carer 6)</i>
	<i>Inter-professional liaison</i>	<i>...they [the ESD team] were the ones that sort of got on to these [builders], got all the things we wanted, we needed. We didn't have to do anything (carer 1)</i>  <i>I would have liked them to have intervened earlier and to have got rid of the carers... We had great difficulty with carers, they were horrendous to be frank...I suppose I would have liked that support (carer 6)</i>
Person-centred service	<i>Individualised care</i>	<i>...they did something really amazing for her which was to get her a wheelchair...she was desperate to get out into the garden...that was such an amazing goal (carer 6)</i>  <i>...she'd say, 'Perhaps there's something else I could be doing now.' So getting the OT to come in on a regular basis was good to help us change (carer 4)</i>
	<i>Staff dedication</i>	<i>They were fantastic, you know, whatever they could do was...It was just amazing...fantastic, I mean they did above and beyond to be quite honest as far as we were concerned. I mean they arrived on time, they cared, they were very caring indeed...extremely friendly, supportive, amazing...such a good relationship with them, a good rapport with them (carer 2)</i>  <i>...they've asked me if there's anything more they can do...if I needed anything they would have been there" (carer 3)</i>
	<i>Emotional support</i>	<i>Their support was amazing, amazing physically and generally sort of emotionally caring for her-making her feel cared for, supported and safe (carer 6)</i>  <i>...they took time when requested to come to me because I was going through a particularly difficult time...they've been incredibly supportive (carer 6)</i>

			<p><i>I don't recall us being asked individually...I sometimes felt that we couldn't open up, or maybe they [ESD team] couldn't open up, because [patient] was there...just a discussion maybe would have been helpful in itself...to prepare us for what we would be feeling like (carer 5)</i></p>
		<p><i>Thorough and motivating care</i></p>	<p><i>...they gave her hope that she would get better. Yes, the whole time they gave her the time, the support and encouraged her the whole time with the things that she wanted to do (carer 2)</i></p> <p><i>Strengthening, balance, mobility, equipment...two visits a day from the team, possibly three...as she started to recover a little bit of strength and mobility, then all the exercises and things all ramped up a great deal and the equipment changed...she had a lot of support from them, not just every day even some weekends you know (carer 6)</i></p>
	Effective intervention		<p><i>...all of them without exception were very hesitant to give her any positive news about the future ...I still think that there are ways of wording things that would give you the positive element and encouragement (carer 6)</i></p>
		<p><i>Improving quality of life through enabling greater independence</i></p>	<p><i>...If my mum had any thoughts about not coping they did everything to help her, they got everything to help her. They got knives and forks, trays, sticky things to put on the bottom of trays. Nothing seemed to be too much trouble at all, it was amazing! (carer 2)</i></p> <p><i>...we go to two clubs...they teach him to speak, to write and his reading has got better and he's started to tell the time...since he's been physically stronger we go out quite a lot and we are going to the shops (carer 3)</i></p>
Patients	Transitions	<p><i>Supporting the move home</i></p>	<p><i>....to come home with nothing would have been quite scary...because you have no experience until this happens to you (patient 1)</i></p> <p><i>I was terribly nervous about coming home and how we'd cope... they were just, she was just so, well welcoming really, and put me at ease and explained exactly what would happen and um we went on from there. So it was a really good start (patient 9)</i></p>
		<p><i>Difficult endings</i></p>	<p><i>...it didn't stop dead, we've had a couple of re-visits, there was a review and things like that...they didn't just abandon me. You always felt there was still a link and if necessary I could ring them and talk to them" (patient 1)</i></p>

		<p><i>...I did depend on them. And they were so helpful to me. And um it's just a big gap, this great gulf really, having someone come three times a day and then suddenly they're not coming anymore (patient 9)</i></p> <p><i>...they supported me, everywhere, and I, I felt abandoned when they left (patient 10)</i></p>
	Access to valuable information	<p><i>They left with the sheets to carry on the exercises...they were more than helpful and they explained everything, you know, as we went along (patient 5)</i></p> <p><i>...they couldn't have been more helpful...did a lot of work for us researching into um, what kind of care I could have after they'd gone and she prepared a dossier of ideas...she set all that up really (patient 9)</i></p> <p><i>...in amidst of all these people what I wanted was one person who I could ask questions of and who'd be able to give me answers, which was not the case...and it really ought to be a doctor as well (patient 7)</i></p>
Knowledge sharing		<p><i>...nobody can actually say to you what fatigue management actually is...it says things like, 'Go to bed in the afternoon.' I'm sure my employer would be delighted if I did that! (patient 8)</i></p>
	Unprepared for the future	<p><i>...they do say to you that 'Well yes it may come back but no it might not, and you might wake up in two years' time and find it comes back, no-one quite knows', but in the meantime life can be quite frustrating and it can be quite a struggle (patient 8)</i></p> <p><i>...everything they did was positive, but the humdrum of life is...they've done their bit but it didn't prepare you (patient 3)</i></p> <p><i>...there is this horrible feeling of 'Why didn't anybody tell me it would be like this?' Well they can't, because for each and every one it's different (patient 8)</i></p>
Person-centred service	Individualised care	<p><i>...they pushed me as much as I was prepared to take, which was a lot (patient 4)</i></p> <p><i>...they tried very hard to tailor things that they were doing to what my specific needs were...they tended to be quite holistic about what they were doing and they were quite interested in weaving it into your life (patient 8)</i></p>



	<p><i>I was terribly impressed, because she said, 'Would you like your hair washed?' and I nearly wept because I hadn't had my hair washed for weeks (patient 9)</i></p> <p><i>...she said, what was it, 'What would you like to do?' And I said, 'You know, I would like to get up those stairs if I could.' And she said, 'Well come on then!' And she, she got me up the stairs (patient 10)</i></p> <p><i>Containment</i></p> <p><i>...everything they said they were going to do they did (patient 1)</i></p> <p><i>These people were fantastic...tremendous support...exceptional really (patient 4)</i></p> <p><i>...they said if ever I needed them to just call them and so I knew it was there if ever I needed it (patient 5)</i></p> <p><i>...they're very thoughtful about the type of people they appoint cos everybody was just really nice, you know just chatty and helpful...they helped me enormously (patient 9)</i></p> <p><i>They never seemed in any hurry to go, though I know they had, they had other things to do...it meant a great deal to me...it was such a comfort....she [case manager] was our safety blanket...it was a life line actually (patient 10)</i></p> <p><i>I think that almost anyone is going to be in the same position because they are suddenly struck down...so it's nice to think that there are such people you can call upon (patient 7)</i></p> <p><i>I really believe that if I still needed it they would have still come (patient 3)</i></p> <p><i>I was vaguely aware they were under pressure to get rid of me...I just got the impression that they were under pressure...which wasn't fair because it was, you know it's a really good service (patient 9)</i></p> <p><i>Emotional support</i></p> <p><i>I think this is where [staff name] was really good, because she knew what had happened, and talking to her was a huge help (patient 9)</i></p>
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	<p><i>[staff name] came at the second visit, he began to make sense, he just talked to me and he put things in perspective (patient 10)</i></p> <p><i>I didn't receive any sort input from them...I had to go back to address that at a later date...because instantly you're just relieved that it's not as bad as it might have been (patient 8)</i></p>
Supporting the family	<p><i>...my husband was really badly affected actually and he found it really difficult to cope but you know [staff name] used to come along...and talk to him...[it] was particularly helpful actually (patient 9)</i></p> <p><i>...they talked to him about all the exercises and things they were doing. Um, I don't think they engaged him in how much he was going to find it difficult to live with someone who is recovering (patient 8)</i></p> <p><i>...there were no secret things. There didn't seem any necessary point in them contacting her (patient 3)</i></p>
Thorough and motivating care	<p><i>I think they sort of give you a perspective of there's nothing that you can't do if you persevere...And they said things will get better each day, which they have done (patient 5)</i></p> <p><i>I think within any confines of what they could offer they offered me an incredible amount (patient 4)</i></p>
Effective intervention	<p><i>It wasn't the basics...I could see they were making a difference...They'd done it so well...They'd helped and I was still progressing (patient 1)</i></p> <p><i>...people kept telling me 'oh it's a long time' 'it's a long time' 'it's a long time'... I did very little of the exercises because I found that they tired me out very quickly so I more or less gave up (patient 7)</i></p>
Improving quality of life through enabling greater independence	<p><i>...she just showed me simple exercises to do around the house and I'm sure thanks to her, I got back up and everything was good...[the ESD team] got me into a position where I could go back to work (patient 3)</i></p>

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*Doors are opening; I'm back at work for 2 months! That's what I wanted, it's been an ambition now I'm fine (patient 4)*

*Well when I came home I couldn't lift that...Now I can do all of those easily...getting my own breakfast and washing my own stuff up (patient 2)*

*...introduced me to...a group...such a support, in cycle activity and all sorts of things (patient 10)*

*...if they had names or numbers of local support groups without me having to find them out myself for like stroke or anything else (patient 1)*

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## **Carer Themes**

### **Transitions**

Carers described having positive experiences of the ESD team's involvement with transitions into and out of the service. There was a sense that the team were thorough in their preparations, allowing patients to feel safe and supported despite a change in service provision.

***Facilitating the move home*** Carers reported being pleased that the ESD team were involved in helping the patient move back home and that they were involved from the hospital stage and helped prepare for the transition.

***Well-prepared endings*** Carers talked about being given plenty of notice that the team's involvement would be coming to an end and that this was done as a phased withdrawal rather than an abrupt finish. Where follow-on services were involved, carers reported that a detailed hand-over was carried out.

### **Knowledge Sharing**

Throughout the interviews there was a sense of overarching satisfaction with how information was provided and shared. The importance of this was evidenced by how frequently carers discussed the impact of communication on their experience of the service.

***Access to valuable information*** Nearly all of the carers reported having information conveyed to them in useful ways. Carers referred to the ESD team as experts who provided key information and advice that they would not have accessed otherwise; there was a consensus that this provided a sense of security and reassurance.

***Uncertainty about the future*** There was some lack of clarity as to the prognosis for loved ones in the future. This created some uncertainty as to whether there was more that could have been done or that they could be doing now and with this a sense of 'stuckness'. However, carers also showed an appreciation that the ESD team could not be expected to hold all of the answers.

***Keeping the family informed*** Carers described being kept involved in the rehabilitation process to some extent, with several mentioning formal family meetings.

***Inter-professional liaison*** Most carers mentioned that the ESD team communicated with other professionals and services on their behalf. This was usually reported to improve the carers' and patients' experiences; carers appreciated the ESD team helping them to address potential difficulties. However, one carer reported that she felt the team should have stepped in sooner to liaise with the care service she was employing and help her find an alternative.

### **Person-Centred Service**

There was an overwhelming sense from the interviews that the ESD team held each individual person at the core of their interventions. Carers talked about how much they valued being dealt with in a sensitive and thoughtful manner.

***Individualised care*** Carers described the support from the ESD team being tailored to the patient's and family's needs. This included working collaboratively to develop goals, being flexible and adapting sessions to suit the patient's changing needs.

***Staff dedication*** Carers described the members of the ESD team as reliable, often giving examples of how they would go the extra mile to help. This included being available to both patients and families when needed, and building good relationships. It was evident that these staff qualities helped carers to feel secure and to trust the ESD team.

***Emotional support*** Running through the interviews was the suggestion that the ESD team's support offered a crutch to carers and patients in a difficult time. This was relevant across several themes but the importance of emotional support was specifically highlighted. Carers reported that the team had engaged in conversations with patients about how they were coping, offering additional psychological input where this was indicated. Most carers discussed being aware that support was available for them and how valuable this was. One carer noted that they were not offered individual support, and that this would have been greatly appreciated.

### **Effective Intervention**

By far the most prevalent theme for carers; carers discussed how instrumental the ESD team's support was to helping the patients adapt to their new circumstances and improve their capabilities. The interventions were described as being professionally delivered with a level of quality that went beyond expectation.

***Thorough and motivating care*** Carers remarked on the breadth and intensity of the practical support offered by the ESD team. They described a holistic approach being taken where each area of functioning was assessed and addressed appropriately. Patients were encouraged to achieve their goals through instilling hope and the provision of targeted support. However, one carer also noted that the team seemed to hold back from instilling what may have been considered 'false hope', and that this was perplexing and potentially unhelpful.

***Improving quality of life through enabling greater independence*** Carers noted ways in which the ESD team helped patients to overcome hurdles and engage more with life. This included the provision of equipment, access to support groups and community activities, and focusing on activities of daily living to increase autonomy.

### **Patient Themes**

#### **Transitions**

Throughout the patient interviews there was discussion of changing circumstances and how these were experienced. In relation to the ESD team this focused on moving home from hospital and how the ESD team enabled patients to feel supported at this time of uncertainty; the end of the ESD team's involvement was discussed as a time of change that was quite difficult for patients to adjust to.

***Supporting the move home*** Patients discussed how the ESD team were involved either from the hospital stage or immediately as they returned home and that this was a huge relief. Several patients described how the involvement of the ESD team from an early stage helped them feel supported in facing the unknown.

***Difficult endings*** Patients reported that the end of the ESD team's involvement was gradual and they were given follow up sessions to re-assess them at a later date. However, many patients reported that despite knowing that the team couldn't come forever, it was difficult saying goodbye to them. Some patients reported feeling that there was more that could have been achieved and for several patients there was a sense of loss and feeling suddenly alone with the impact of the stroke.

### **Knowledge Sharing**

Throughout the patient interviews was the sense that clear and relevant communication was important to enhance patient's sense of wellbeing. Generally the ESD team appeared to meet these needs but there were some reported instances where important concerns were not discussed as effectively as the patient would have liked.

***Access to valuable information*** Patients discussed how the ESD team shared key information. This included detailing the rehabilitation process and providing accessible materials to aid with this, as well as being available to offer their expert advice. This appeared to provide a sense of security and reassurance. However, a few patients reported feeling that the information they needed was not always forthcoming and that this created a sense of frustration and anxiety.

***Unprepared for the future*** A minority of patients reported feeling they were inadequately prepared for how they might be affected by the stroke as time went on and that discussions about potential future outcomes and how to address these may have been helpful. However, it was acknowledged by all three of these patients that the diversity between stroke survivors would make it hard to provide every patient with the right information.

### **Person-Centred Service**

There was a consensus that the ESD team adapted their interventions to the needs and desires of the patients in a respectful way. This was by far the most prominent theme for patients and created a sense that the responsiveness of the ESD team helped patients to feel more secure.

***Individualised care*** Patients reported that the care they received was tailored to suit their needs. This included collaborative goal-setting and varying the duration, intensity and focus of sessions to respect the patients' wishes. There was a sense that this approach was helpful in engaging and motivating patients to achieve their goals.

***Containment*** Patients described the members of the ESD team as personable, reliable and available, often reporting that their input went beyond expectation. The dependability, responsiveness and warmth that the patients reported receiving from the ESD team appeared to create a sense of safety in a potentially challenging time. It was evident that this was an invaluable asset for the patients. However, some patients also reported sensing that the team had limited resources and that this somewhat disrupted the sense of security that had otherwise been created.

***Emotional support*** Focused emotional support was also discussed as an important area, with some patients receiving formal psychological input and most patients being offered psychological support should they need it. However, two patients were not offered psychological input and felt this would have been extremely beneficial. Interestingly they were two of the three patients who had returned to work after having a stroke and both remarked that their psychological wellbeing did not become a major concern until after their return to work. In both cases psychological help had to be sought from external sources at a later date.

***Supporting the family*** Patients reported mixed experiences around the ESD team involving family members. Most patients reported that their families were included in meetings and kept updated on a regular basis; in two cases the patient's spouse received psychological support themselves. In all cases family inclusion was deemed to be valuable. However, two patients described feeling that it would have been beneficial to have more input to assist their families to prepare and adjust on a psychological level. Three patients reported that the ESD team did not directly attempt to involve their families but that this was appropriate and acceptable.



### **Effective Intervention**

Patients discussed how the interventions provided by the ESD team helped them to adapt and progress whilst increasing their independence. There was an appreciation that the care provided went beyond expectation in terms of breadth and intensity and that this helped to create hope and achieve goals.

***Thorough and motivating care*** Patients discussed the comprehensive nature of the care they received. It was generally agreed upon that the ESD team went to great lengths to assess all areas of the patients' abilities and provide intervention where it was needed. These patients also described how receiving broad and intensive care, as well as the positive attitude of the ESD team, helped them to feel more optimistic and motivated. However, two patients reported feeling somewhat de-motivated by comments from the team and two patients noted that at times the intensity of the intervention could be overwhelming.

***Improving quality of life through enabling greater independence*** Patients conveyed how their lives had been changed for the better through engaging with the ESD team's support. This was linked to improvements in physical ability that had been facilitated by the ESD team. Additionally, two patients mentioned being advised of support groups and activities available to them and that this assisted them to integrate with their communities more and achieve greater independence. Two patients discussed how helpful it would have been to be signposted to such resources.

### **Discussion**

#### **Relevance of these Findings to Previous Literature and Guidelines**

The themes from patient and carer interviews suggest that the BANES CNSS ESD service is providing high quality care that is generally very well-regarded by service-users and has a considerable positive impact on people's lives. Within the data is qualitative evidence that many of the key functions of an ESD team, as outlined by NICE (2013), are viewed by service-users as being met by the service. This includes: continued inter-disciplinary communication; rehabilitation goal setting; provision of information and care for stroke-

related needs; and supporting self-care, community activities, social identity and return to work.

Areas of concern that were identified in previous qualitative research with service-users included limited support for carers and inadequate emotional support (Cobley et al., 2013; Taule et al., 2015). Carer support and emotional aspects were also found to be important in this study, although were experienced in a more positive light. In terms of carer support, interviewees indicated that carers were being involved to an appropriate level and kept well-informed, with both indirect and direct support being offered to carers to help manage the practical and psychological aspects of caring for a loved-one after a stroke. However, there were some cases where individual emotional support was reportedly not offered and would have been valued by the service-user, highlighting the importance of ensuring that carers' psychological needs are considered. Both carers and patients stressed how valuable they found the emotional support that the team provided to patients. This was seen as being provided by all staff in the course of their visits, creating a sense of containment, and being offered as a focused intervention by psychologists when indicated. Again, the minority of patients who were not offered psychological input noted that this would have been useful, and was something they had to seek out at a later date.

In contrast to previous findings that endings and transitions out of ESD services were experienced as abrupt and at times not well managed (Cobley et al., 2013), service-users from the BANES CNSS ESD service reported that the end of care was well prepared and phased, with detailed hand-overs to other services taking place. However, it was very apparent in the patient interviews that, despite knowing the support would come to an end, the cessation of the team's involvement was a difficult experience. Both carers and patients discussed feeling unsure of the future; for carers this was related to what the next steps would be in terms of rehabilitation and the patient's prognosis; for patients this was around how their lives would look and how they would adapt. This is related to Taule and colleagues (2015) finding that engendering hope was an important part of stroke-rehabilitation staff's work. Generally, the findings of this study suggest that the BANES CNSS ESD service is experienced as encouraging and positive about the future. However, some carers and patients commented on feeling unsure about what lay ahead, or even at times that the service were hesitant to give them 'false-hope'. Nevertheless, there was recognition by service-users that each stroke affects

families in a unique way and that the team could not be expected to hold the answers to all questions.

Taken together these considerations suggest that the service is delivering care that largely addresses previously identified areas for improvement. However, the fact that service-users noted when carer support, emotional support or information sharing were lacking confirms that these are important elements to concentrate on.

### **Comparing Carer and Patient Themes**

Despite significant overlap between carer and patient themes and sub-themes (particularly in relation to individualised care), there were some interesting differences. Carer interviews referenced the practical aspects of the ESD team's involvement more frequently. In contrast, the patient interviews had a much stronger focus on psychological and emotional aspects of care. The differences in carer and patient themes are likely related to the different needs and experiences of these two groups. Carers often take the role of organising support and overseeing how this is implemented; therefore factors such as inter-professional liaison and having accessible information about rehabilitation and stroke, are likely to be viewed as important. In contrast, patients have experienced an event that may have challenged their self-identity and previous capabilities; therefore factors such as feeling emotionally supported and needing detailed and personalised information about how to move forward are likely to be viewed as important.

### **Recommendations and Improvements**

After the interviews were analysed, the lead researcher (MC) met with the service manager, team lead, and clinical neuropsychologist (LD), to present the findings and discuss how the resulting recommendations could be implemented in the service context. Following this meeting the recommendations on how the service might be improved based on the service-user feedback were finalised and circulated (see Table 2.3 for a summary and Appendix E for more detail).

The team had a very positive response to the findings of the study. In particular they were keen to hear suggestions about better managing endings; they reported that they had experienced this as a sometimes difficult experience for patients but had been unclear how to

capture this or seek to address it. The staff fed-back that it was encouraging to hear that service-users found their care to provide containment and emotional support as this was something they often looked to the psychologists to provide. The suggestion that regular psychology training sessions be implemented in order to further support staff to develop skills in this area, as well as have some space to reflect on difficult situations, was very warmly welcomed.

Table 2.3

*Summary of Recommendations Shared with the Team*

Area	Suggestions	Next steps
Beginnings	<ol style="list-style-type: none"> <li>1. Protocol ‘beginnings’ to ensure the key areas highlighted by the themes as useful are always considered</li> <li>2. Touching on endings at the start</li> </ol>	<ol style="list-style-type: none"> <li>1. Create a protocol for the initial session(s)</li> </ol>
Endings	<ol style="list-style-type: none"> <li>1. Implement discussions about endings at the start</li> <li>2. Implement an endings meeting. This could include providing a leaflet (e.g. ‘Moving On’) detailing the impact of endings and providing information about available services</li> <li>3. Provide a personalised ‘My next steps’ sheet where on-going exercises and suggestions for community activities are detailed</li> </ol>	<ol style="list-style-type: none"> <li>1. Decide when might be the best timing for the endings meeting</li> <li>2. <u>Endings leaflet to be designed</u></li> <li>3. <u>‘My next steps’ sheet to be designed</u></li> </ol>
Information provision	<ol style="list-style-type: none"> <li>1. Ensuring information addresses individualised needs – using review sessions to check if there are any questions or if information already provided needs to be revisited</li> </ol>	<ol style="list-style-type: none"> <li>1. Implement ‘information provision review’ as part of review meetings</li> </ol>
Team as expert	<ol style="list-style-type: none"> <li>1. Continue to take a holistic approach to care, helping to advise and guide patients directly as well as signposting to resources</li> <li>2. Where professional liaison is required it may be useful to model this for families to help build their confidence to contact services independently</li> <li>3. Continue to have ‘hand-over’ meetings with follow-on services where relevant</li> </ol>	<ol style="list-style-type: none"> <li>1. ESD team to consider modelling contacting services for patients where possible</li> <li>2. To reassure team of value of taking time to help with advice and information sharing</li> </ol>
Dealing with uncertainty	<ol style="list-style-type: none"> <li>1. The ‘Moving On’ leaflet and personalised ‘My next steps’ sheet should help address some of these issues (see above)</li> <li>2. Support and training for ESD team staff members to help them consider how to manage difficult questions</li> </ol>	<ol style="list-style-type: none"> <li>1. <u>Psychology training provided bi-annually to ESD team staff to consider how to approach challenging questions and reflect on the impact uncertainty may have on them as professionals</u></li> </ol>

Carer/family support	<ol style="list-style-type: none"> <li>1. Include 'discussing the carers' leaflet and 'adjustment with family members' on the 'induction checklist' (see above)</li> <li>2. Check in 1:1 with family members where possible</li> <li>3. Signposting carers to support options when their needs go beyond the scope of the ESD team</li> </ol>	<ol style="list-style-type: none"> <li>1. Induction checklist to be developed (see above)</li> <li>2. Introduce a checklist for review meetings to ensure family perspectives are being sought independently from patient where possible</li> <li>3. <u>Including carer support options on the 'moving on' leaflet and/or the 'my next steps' sheet (see above)</u></li> </ol>
Individualised care	<ol style="list-style-type: none"> <li>1. Continue to tailor interventions to suit individual's needs, wants and interests</li> <li>2. To ensure this is being considered and addressed for all patients</li> </ol>	<ol style="list-style-type: none"> <li>1. <u>Editing the 'My journal' paperwork to streamline the current information and include important information about the individual case</u></li> </ol>
Goals and instilling hope	<ol style="list-style-type: none"> <li>1. Continue to use Goal Attainment Scaling to collaboratively set and monitor goals</li> <li>2. Consider how to instil hope</li> </ol>	<ol style="list-style-type: none"> <li>1. <u>ESD team to receive supervision around managing tricky situations and working with adjustment at bi-annual psychology sessions (see above)</u></li> </ol>
Psychological input	<ol style="list-style-type: none"> <li>1. For staff to receive regular training around how to assess and respond to psychological needs</li> <li>2. For team to receive regular training on simple psychologically informed recommendations and resources they can share with patients and carers</li> <li>3. For psychological needs to continue to be addressed at the 6 month review – ensuring this is not just looking at the PHQ9 and GAD7 but also questions asking how they have been emotionally and how they are managing</li> <li>4. Literature about access to further support gone over at 6month review</li> </ol>	<ol style="list-style-type: none"> <li>1. <u>ESD team to receive input from psychology around assessing and responding to psychological distress at bi-annual psychology sessions (see above)</u></li> <li>2. <u>For the review process to be re-visited to see if there is a need to introduce a protocol where discussions (as well as measures) about psychological needs are included</u></li> </ol>
Community and social engagement	<ol style="list-style-type: none"> <li>1. Inform all patients of available community and social activities that may suit their individual interests and needs</li> <li>2. Consider online-forums as a form of social support</li> </ol>	<ol style="list-style-type: none"> <li>1. To liaise with the Stroke Association about resources for younger stroke survivors and to see if this is being offered to younger patients. If it is not, considering how this can be included</li> </ol>

		2. To consider adding personalised activity recommendations to the 'My next steps' sheet and delegating this as a responsibility to the case manager
On-going service review	1. Consider how patient feedback is collated and used to inform practice 2. Introduce an annual focus group 3. Involvement of patients and carers in service development	1. To review current feedback forms with service-users 2. <u>To implement annual service-user feedback forums</u> 3. To increase attempts to involve service-users in service development meetings and new staff interviews

*Note: 'Next steps' that the lead authors are involved in implementing have been underlined*

At the time of writing, the service had implemented several of these suggestions. In conjunction with the lead author, the clinical neuropsychologist in the team had developed a leaflet about endings to prepare service-users for some of the challenges this can present (Appendix F). The leaflet will be discussed with service-users in the initial sessions and then re-visited near the end of the team's involvement. A 'My next steps' sheet will also be introduced in the 'endings' sessions to ensure any remaining concerns or questions are addressed and a clear outline developed with the patient of their individual plan looking forward. The team have already held a service-user day with focus groups covering key topics; they plan to implement a yearly focus group on a smaller scale to compliment the service-user feedback that is already collected. Service-users are also being invited to assist with key service decisions, such as hiring new staff. Bi-annual psychological training days are being implemented to support staff to feel confident in dealing with high emotion situations, mental health needs and their own wellbeing; the importance of this has been highlighted previously (Morris, 2016). This will include a presentation about this study, delivered in the first instance with support from the lead author.

Other recommendations for improvement are yet to be actioned. The service plans to revisit the current 'My journal' to see if this can be amended to cover important individualised information in a briefer and more accessible manner to increase its utility. The team are also planning to make protocols for key phases of treatment, such as beginnings, review sessions and endings. Additionally, the team plan to re-examine how review meetings are conducted to ensure that service-user questions and needs are being thoroughly re-assessed in a meaningful way that

leads to areas of dissatisfaction being appropriately addressed. The team also plan to review how the opinions and needs of those not included in this study (see Limitations section) might be taken into consideration; for example discussing challenges that staff have faced in working with such clients and thinking together about ways to address these in the future.

### **Limitations and Considerations**

There are several limitations to this study. Despite inviting all eligible service-users to take part, the sample is not representative of all service-users who are supported by the team. The eligibility criteria ruled out those who were severely impaired in language or cognition. Carers whose family members had died or were receiving palliative care were not invited. Additionally, there were several people who declined to take part in the interviews. Considering these factors, it is likely that those who agreed to be involved in the study had different needs than those who did not. Although the team's caseload is largely White British, there are some service-users with different ethnicities, yet the sample failed to engage any participants who were not White British. This is particularly relevant given research demonstrating that ethnic minorities may have a different experience of health services (Cruickshank & Beevers, 2013). A strength of the study is that mild-moderate aphasias were accommodated, allowing greater representation of people who have aphasia after stroke than many other papers.

### **Recommendations for future research**

Future research that seeks to gather the views of hard-to-engage service-users would be valuable. This would help to ascertain if the research into service-users' experiences of ESD teams so far can be generalised to all service-users, or whether it is specific to those who are able and willing to engage with qualitative research. It would be useful for services that implement changes to measure any improvements in outcome, for example service-user satisfaction, that come about as a result of these changes. This will elucidate specific factors that may be particularly effective at improving ESD services' care provision.



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**Main Research Project: An Experimental Investigation  
into the effect of State-Anxiety on State-Paranoia in People  
Experiencing Psychosis**

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Please see Appendix G for instructions to authors.

## **Abstract**

**Background and Objectives:** The threat-anticipation model of paranoia suggests that a number of factors interact to form and maintain paranoia, with anxiety playing a key role. There is strong evidence to suggest that anxiety is associated with paranoia in clinical and non-clinical samples. However, no research to date has directly manipulated anxiety to investigate if state-anxiety has a causal role in state-paranoia in clinical populations.

**Methods:** 22 participants with a psychosis-spectrum diagnosis took part in a repeated-measures, experimental, cross-over design. Participants took part in a neutral-mood and an anxious-mood induction with levels of state-anxiety, state-affect and state-paranoia being measured before and after each condition.

**Results:** State-paranoia was significantly higher after the anxious condition compared to the neutral condition. State-anxiety and state-paranoia were significant predictors of levels of state-paranoia after the anxious condition. When both predictors were included in a regression model, only negative-affect was a significant predictor of state-paranoia after the anxious condition.

**Limitations:** There were a number of methodological limitations that are outlined in the discussion.

**Conclusions:** State-anxiety and negative-affect may both be involved in the maintenance of paranoia in clinical populations, as predicted by the threat-anticipation model. However, negative-affect may be more important in state-paranoia than state-anxiety in clinical populations. Interventions that seek to reduce state-affect may be beneficial in managing state-paranoia. Further research is warranted to explore the suggested clinical and theoretical implications of these findings.

**Keywords:** paranoia; anxiety; psychosis; schizophrenia; affect

## **Background**

Current research has begun to consider specific experiences that may be part of schizophrenia or psychosis spectrum presentations rather than the diagnosis itself due to concerns about the validity, reliability and utility of such diagnoses (Bentall, 1990; Boyle, 2002; Garety & Freeman, 2013). Paranoid delusions can be a particularly distressing experience that are reported by 70% of people with a first episode of psychosis (Freeman & Garety, 2014), as well as by people with other diagnoses and non-clinical populations (Bebbington et al., 2013). Research comparing clinical with non-clinical groups experiencing such beliefs suggests that it is not the content of the beliefs that leads to distress and help-seeking, but rather the meaning attached to the thoughts and the consequences of this for the individual (Peters, 2001).

### **The Threat-Anticipation Cognitive Model of Paranoid Delusions**

The threat-anticipation model of paranoia suggest that paranoia is essentially anticipation of threat from others and develops as a way to explain unusual experiences (Freeman, 2007; Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002). The model posits that triggers such as poor sleep, drug-taking, and stress can lead to anomalous internal experiences such as perceptual irregularities or heightened arousal. Such experiences can also lead to emotional changes, particularly anxiety and depression, and activate reasoning biases. Attempts to find meaning in the anomalous experiences involve assessing both internal and external information, for example increased arousal (internal) and coincidences in events (external). Interpretations of both the internal and external evidence are influenced by the activated affect, reasoning biases and arousal, as well as by pre-existing beliefs and life experiences, towards making threat interpretations. As such, it is the interpretation of the anomalous experience, rather than the experience itself, that leads to paranoia. The model points to stressful life events, urbanicity, social isolation, trauma and previous life experiences as being important determinants of whether anomalous experiences will be interpreted as threatening. This is in part due to how such experiences impact on the individual's knowledge base, memories, personality, emotional reactions and decision-making processes (Freeman, 2007).

Once paranoia has developed, the model proposes that it is maintained by an interaction of anxiety, depression, reasoning biases and safety-seeking behaviours. These factors encourage confirmatory evidence to be sought and accepted, and prevent the processing of disconfirmatory evidence, thus maintaining the paranoia. The content of the paranoid delusions in turn reinforces anxiety, depression, reasoning biases and safety behaviours. The model also highlights the positive reinforcement gained when the paranoid delusions are thought to be confirmed due to relief that “it’s not all in my head” and the ability to hold on to existing beliefs, thereby avoiding cognitive dissonance (Freeman et al., 2002).

In summary, the threat-anticipation model of paranoia proposes that an interaction of vulnerabilities (e.g. trauma, deprivation), anomalous experiences (e.g. distorted perception, hallucinations), affective processes (e.g. anxiety, depression), reasoning biases (e.g. jumping to conclusions, confirmatory bias) and safety behaviours (e.g. withdrawal, vigilance for threat) lead to and maintain paranoid ideation. Other cognitive models also highlight these factors as instrumental in the formation and maintenance of paranoia and other psychotic experiences (e.g. Chadwick, Birchwood, & Trower, 1996; Morrison, 2001).

### **The Role of Anxiety in Paranoid Delusions**

Paranoid ideation is the unfounded belief that harm is, or will be, purposefully inflicted on the individual (Freeman & Garety, 2000). Given that anxiety is commonly understood as threat-anticipation, and disorders of anxiety as chronic overestimations of threat (American Psychiatric Association, 2013; Butler, Fennell, & Hackmann, 2010; Wells, 1997), it makes intuitive sense that delusions involving anticipation of harm would be influenced by, and in turn influence, anxiety. Anxiety is given a key role in the threat-anticipation model of the formation and maintenance of paranoid delusions. In fact, Freeman and colleagues (2002) postulate that the presence of anxiety may be one of the defining reasons for the paranoid content of the delusion as compared to, for example, delusions of grandeur where elation may be the dominant affective state. Research using virtual reality environments with non-clinical groups found that paranoid and socially-anxious interpretations of the environment were both predicted by baseline levels of anxiety. Predisposition to hallucinatory experiences distinguished the prediction of paranoid interpretations from socially-anxious interpretations,

supporting the idea that anxiety combines with other factors, such as anomalous experiences, to increase the likelihood of paranoia (Freeman, Garety, Bebbington, Slater, et al., 2005).

The research base supporting the role of anxiety in paranoia is substantial. Anxiety has been found to be associated with paranoia in the general population (Freeman et al., 2011), high-risk groups (Salokangas et al., 2016) and clinical groups (Bosanac, Mancuso, & Castle, 2016; Huppert & Smith, 2005). Both anxiety and worry, a key cognitive component of anxiety, were found to have a dose-response relationship to paranoia in a study involving low paranoid, high non-clinically paranoid and clinically paranoid groups (Freeman, Pugh, Vorontsova, Antley, & Slater, 2010). An experience sampling study found that increases in anxiety predicted the onset of paranoid episodes in people with and without clinical paranoia (Thewissen et al., 2011) and anxiety has been found to predict the persistence of paranoia in high-risk groups (Salokangas et al., 2016). In sum, there is good evidence that anxiety is associated with paranoia.

However, a systematic review (Hartley, Barrowclough, & Haddock, 2013) concluded that, whilst there is convincing evidence that anxiety and depression are associated with psychotic experiences, there is a need for research that explores causal relationships between these affective states and specific psychotic experiences. An experimental investigation in a non-clinical population found that an anxious-mood induction led to significantly greater state-paranoia than a neutral-mood induction and that this was predicted by anxiety levels after the mood induction over and above other mood states (Lincoln, Lange, Burau, Exner, & Moritz, 2010). Furthermore, it was demonstrated that the anxious-mood induction increased paranoia only for those with higher baseline paranoia, adding support to the stress-vulnerability model inherent in cognitive models. However, these results may not be the same in people who have already developed clinically significant paranoid delusions; this remains to be investigated.

Research that helps to elucidate which factors are involved in the formation and maintenance of paranoia is crucial to indicate useful targets for prevention and treatment. Preliminary studies into treatments for anxiety in people with paranoia have had promising outcomes. A cognitive-behavioural intervention targeting anxiety and reasoning biases was found to reduce anxiety and paranoia in people with anxiety disorders; this effect was greater for those with higher baseline paranoia (Giusti et al., 2017). Pilot studies into brief CBT



interventions for worry have found that when worry is reduced, there are significant reductions in paranoid ideation and paranoia-related distress compared to treatment as usual in people with paranoid delusions and psychosis (Foster, Startup, Potts, & Freeman, 2010; Freeman et al., 2015). Further studies that clarify the role of anxiety and other factors in paranoia are necessary to develop and refine theoretical models and clinical interventions. Specifically, research is needed to explore if there is a causal role for anxiety in paranoid thinking and if this interacts with other factors (Freeman, 2007; Hartley et al., 2013).

### **Aims of This Paper**

No study to date has directly manipulated anxiety to see if it has an effect on paranoia in people experiencing such beliefs in the context of clinical psychosis. This study will seek to investigate whether an anxious-mood induction leads to greater paranoia than a neutral-mood induction in people suffering with psychosis and paranoia and, if so, whether this is predicted by anxiety over and above other variables. The results hope to inform theories into how paranoid delusions are maintained in clinical populations, providing additional evidence for cognitive models of paranoia, such as the threat-anticipation model. Results could also indicate whether interventions aimed at managing state-anxiety may be useful for reducing paranoia and related distress.

It is predicted that: (1) the anxious condition will lead to more state-paranoia than the neutral condition; (2) state-paranoia after the anxious condition will be predicted by state-anxiety; (3) state-anxiety will predict state-paranoia to a greater extent than other affective states; and (4) higher trait-paranoia will predict higher state-paranoia after the anxious condition.

### **Method**

Ethical approval was obtained from the NHS Health Research Authority (project ID: 201330; Appendix H) and the University of Bath Ethics Committee (ref: 16-174) prior to conducting this study. Participants gave informed consent before taking part in the study and were fully debriefed at the end of the study.

## **Participants**

Participants were recruited from community mental health teams in the South West of England. Inclusion criteria were: (a) primary psychosis-spectrum diagnosis; (b) experiencing paranoia with at least 50% conviction; (c) aged 18-65; (d) not acutely unwell at present; (e) sufficient English language and cognitive ability to take part in the study; and (f) being supported by a mental health team. Twenty-seven people were initially recruited and five of these were excluded: three due to insufficient levels of paranoia, and two as the neutral condition caused them to feel more anxious than the anxious condition. The remaining 22 participants were aged between 20 to 60 years-old ( $M = 32.82$ ;  $SD = 10.72$ ). The time since first recorded psychotic episode ranged from 0.5 to 27 years ( $N = 22$ ;  $M = 9.13$ ;  $SD = 9.22$ ). Please see Table 3.1 for a summary of additional demographic information.

Table 3.1

*Demographic Information*

	<b>Demographic</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Gender</b>	<i>Female</i>	9	41
	<i>Male</i>	13	59.1
<b>Ethnicity</b>	<i>White British</i>	20	91
	<i>White Other</i>	1	4.5
	<i>White and Black Caribbean British</i>	1	4.5
<b>Employment Status</b>	<i>Unemployed</i>	14	63.6
	<i>Employed</i>	3	13.6
	<i>Part-time Volunteer</i>	3	13.6
	<i>Student</i>	2	9.1
<b>Marital Status</b>	<i>Single</i>	16	72.7
	<i>Cohabiting</i>	5	22.7
	<i>Widowed</i>	1	4.5
<b>Primary Diagnosis</b>	<i>Paranoid Schizophrenia</i>	10	45.5
	<i>Non-Organic Psychosis</i>	7	31.8
	<i>Drug Induced Psychosis</i>	2	9.1
	<i>Schizotypal</i>	1	4.5
	<i>Schizoaffective</i>	1	4.5
	<i>Bipolar with Psychotic Symptoms</i>	1	4.5
<b>Psychiatric Medication</b>	<i>Antipsychotics</i>	17	77
	<i>Antidepressants</i>	6	27.3
	<i>Anxiolytics</i>	4	18.2
	<i>Insomnia Medication</i>	3	13.6
	<i>Alcoholism Medication</i>	1	4.5
	<i>None</i>	3	13.6

## Measures

**Paranoia Checklist** (PC: Freeman, Garety, Bebbington, Smith, et al., 2005). The PC was used to measure paranoia conviction. This is an 18-item self-report measure with statements relating to paranoid ideation. Respondents use a 5-point rating scale to indicate frequency (0 = 'rarely' to 4 = 'daily'), conviction (0 = 'do not believe it' to 4 = 'absolutely believe it') and level of distress (0 = 'not distressing' to 4 = 'very distressing') for each statement. The scale has been found to have excellent internal reliability (Freeman, Garety, Bebbington, Smith, et al., 2005). For the purpose of this study only the conviction questions (18-items) were used and the terms 'people' and 'someone' were changed to 'others' and 'someone or something' respectively based on feedback from the pilot study that paranoid ideation was often experienced in relation to entities as well as people. Responses were summed with higher scores indicating more paranoia conviction (range: 0 – 72). Cronbach's alpha was .88 in this study, indicating good reliability.

**Psychotic Symptoms Rating Scale – section B** (PSYRATS-B: Haddock, McCarron, Tarrier, & Faragher, 1999). The PSYRATS-B was used to measure degree of trait paranoia. This scale consists of six clinician-administered questions rated on a 5-point rating scale from 0 (none) to 4 (extreme). The scores are summed with high scores indicating greater severity of delusions; in this study only paranoid delusions were enquired about (range: 0-24). The scale has been found to have excellent reliability (R. Drake, Haddock, Tarrier, Bentall, & Lewis, 2007).

**Forms of Self-Criticising and Self-Reassuring Scale** (FSCRS; Gilbert, Clarke, Hempel, Miles, & Irons, 2004). The FSCRS was used to measure self-criticism and self-reassurance using the short version of the scale (Mayhew & Gilbert, 2008). The results of this measure are reported in a separate paper (Cowles, Chapman, & Hogg, *in preparation*).

**Brief State Measure.** The Brief State Measure was used to measure fluctuations in state- anxiety, affect, paranoia and paranoia-related distress. This is a 17-item self-report measure designed specifically for this study to measure variables of interest in a short timeframe.

All statements on the Brief State Measure were presented on a 10cm visual analogue scale (VAS) with participants drawing a line where they felt that each statement applied to them *right now* (anchors: ‘not at all’, ‘extremely’). The order that the questions were presented in was different each time.

The items were derived from existing measures and previous research studies:

- *State-paranoia* was measured using the 3-item change sensitive version of the PC, which has been found to have good psychometric properties ( $\alpha = .74$ ; Schlier, Moritz, & Lincoln, 2016).
- Measures of *positive-affect*, *negative-affect*, and *anxiety* were derived from a reliable measure of state-affect ( $\alpha = .81$  to  $.94$ ; Stemmler, Heldmann, Pauls, & Scherer, 2001). The original, unnamed measure included five affective states (shame, anger, sadness, fear, happiness) rated on a 0 – 10 scale. Other studies looking at anxiety and paranoia have utilised this scale in modified formats (e.g. Ascone, Sundag, Schlier, & Lincoln, 2016; Lincoln, Hohenhaus, & Hartmann, 2013; Lincoln et al., 2010). In this study these five descriptors, along with two descriptors that were also in Stemmler et al.’s (2001) study to indicate arousal (calm, relaxed), were split into three subscales in order that negative, positive and anxious affective states could be explored separately. The following words were presented after the statement ‘I feel...’:
  - *State-anxiety sub-scale* – ‘anxious’, ‘calm’ (reversed), ‘relaxed’ (reversed)
  - *State-negative-affect sub-scale* – ‘ashamed’, ‘sad’, ‘irritated’
  - *State-positive-affect sub-scale* – ‘happy’

For the anxiety and negative-affect scales the mean score from the three items was used; higher scores indicated higher affect (range: 0 – 10).

- *Paranoia-related distress* was measured with the item, ‘I am distressed by thoughts of others wishing me harm’.
- *Self-reassurance and self-criticism* were measured with six items; these will be discussed elsewhere (Cowles et al., *in preparation*).

Cronbach’s alphas for each sub-scale with more than one question on the Brief State Measure were calculated for each time point. Paranoia had acceptable to excellent reliability ( $\alpha = .77$  to  $.91$ ), anxiety had questionable to good reliability ( $\alpha = .65$  to  $.87$ ), and negative-affect had questionable to acceptable reliability ( $\alpha = .61$  to  $.75$ ).

Please see Appendix I for a copy of the measures used in this study.

## **Materials**

See Appendix J for a copy of the scripts used in this study.

**The Brief Relaxation Script** was used before each condition. This was based on previous studies looking at paranoia (e.g. Ascone et al., 2016; Lincoln et al., 2013).

**The Imagery Recall Script** was used to enhance remembering of the chosen event. This included prompts to elicit *in-sensu* memory recall (e.g. what can you see/hear/feel? What are you thinking/feeling?). This was based on previous studies looking at paranoia (e.g. Ascone et al., 2016; Lincoln et al., 2013).

**The Compassionate-Colour Imagery Script** was used to reduce any distress and elicit soothing feelings. This was based on compassion-focused therapy techniques and existing imagery scripts (e.g. Gilbert, 2010).

## **Design and Procedure**

A randomised, experimental, independent groups design was initially planned for this study. However, given predicted problems with recruitment, a randomised, experimental, crossover design AB/BA was used to allow repeated measures statistical analyses to be performed and to avoid low power issues associated with the independent groups design.

Participants were informed that the study was looking at the impact of recent memories on thoughts and feelings. Participants provided demographic information before completing the PC and PSYRATS-B; those who did not have a current paranoid delusion as defined by Freeman and Garety (2000) and measured by the PC, or who were not at least 50% convinced by these thoughts as measured by the PSYRATS-B, were excluded from the study ( $n = 3$ ). Following this the FSCRS was completed. Participants were then randomised to either the anxious condition or the neutral condition first by the experimenter picking the letter A or N out of an envelope containing an equal number of both letters.

The Brief State Measure was completed. The participants were then asked to recall a recent (within the last two months) event that either caused them to feel anxious, but that they did not consider to be traumatic (anxious condition), or that they considered to be emotionally neutral, such as a regular daily activity (neutral condition). Once an appropriate event had been identified, participants were guided through the brief relaxation script. They were then guided through the in-sensu imagery recall script until the image was rated as at least 60% vivid where possible. When ratings were less than 60%, sensory prompts were used to try and elicit more vividness. If ratings remained below 60% vivid data was still included in the study. The imagery was finished after approximately 4 minutes. The Brief State Measure was completed again. Following this, participants were guided through the compassionate colour imagery exercise. The Brief State Measure was completed again. There was a minimum 20-minute break before the procedure was repeated for the experimental condition that the participant had not yet completed.

Finally, participants were asked to complete a short discussion about their experiences of recalling the memories, how they found using the compassionate imagery, and what they thought the study was about. Participants were debriefed, paid £10 for their time, and given written and verbal instructions about how to continue using the compassionate imagery plus other anxiety-management techniques.

The study lasted for approximately 90 minutes. Please see Figure 1 for an overview of the study procedure. Outcomes and feedback relating to the FSCRS and the compassionate imagery will be reported in a separate paper (Cowles et al., *in preparation*).

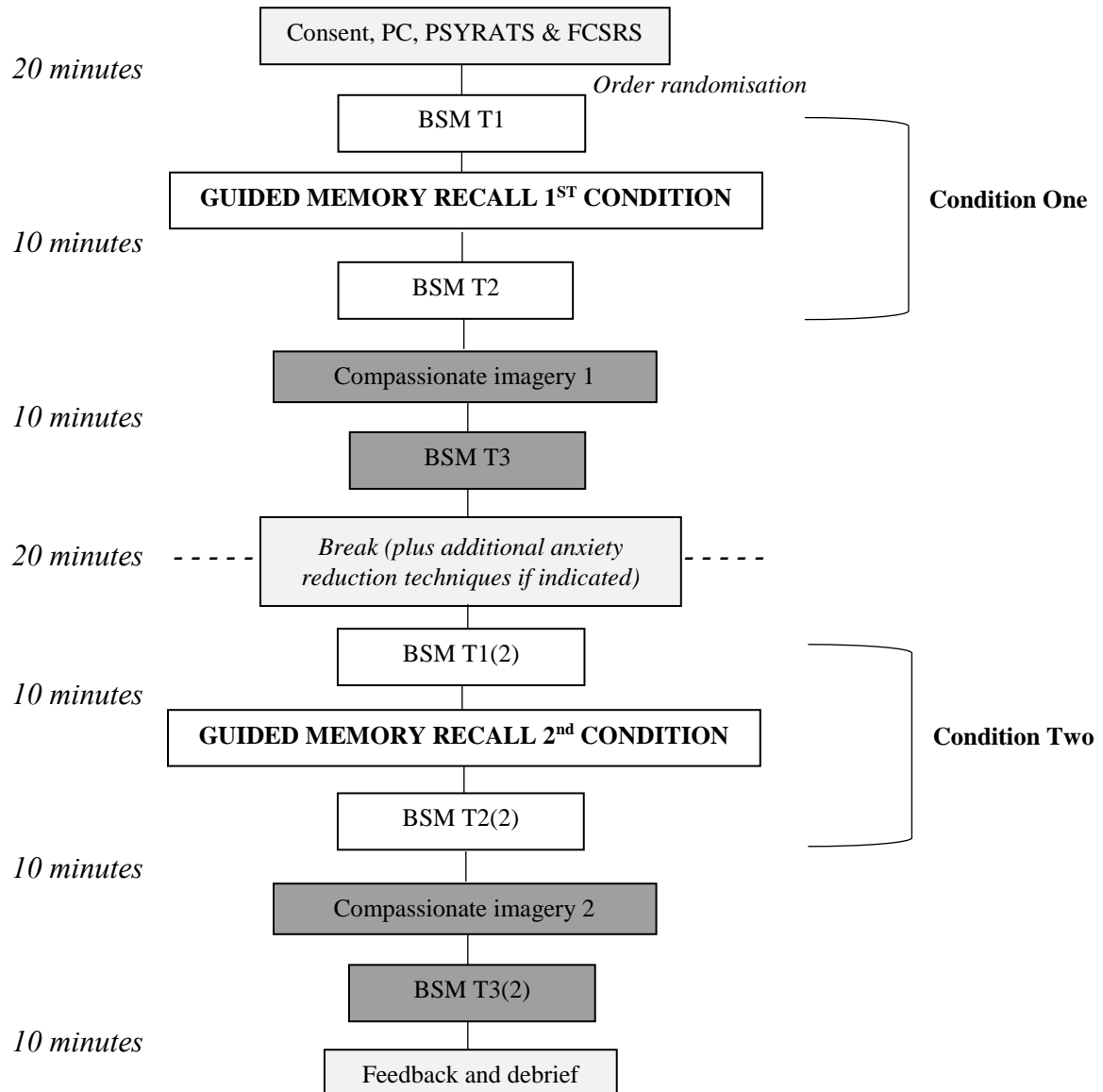


Figure 1. Flow Diagram of Study Procedure with Time Estimates. (Note: Sections in dark grey were not analysed as part of this paper. Results section refers to ‘pre’ (T1) and ‘post’ (T2) the memory recall conditions. BSM = Brief State Measure. Dotted line denotes end of first-condition)

### Statistical Analysis

Please see Appendix K for power analyses.



Due to predicted issues with recruitment, the study was under-powered to perform parametric tests on the independent group data. Please see Appendix L for non-parametric independent-groups data based on each participants' first condition only.

For this reason, analyses were carried out on the repeated-measures data. The effect of the anxious condition compared to the neutral condition on each variable of interest (paranoia, distress, anxiety, negative- and positive-affect) was explored using a 2x2 repeated-measures analysis of variance (ANOVA) with within-subjects factors 'time' (pre, post) and 'condition' (anxious, neutral). Significant interactions between time and condition were furthered analysed using paired t-tests to analyse which variables were significantly different between the two conditions. Once the impact of the anxious versus the neutral condition had been identified, regression analyses were used to assess whether state-anxiety predicted state-paranoia and whether this was to a greater extent than prediction by negative-affect. Simple linear regression was used to test if trait-paranoia predicted state-paranoia after the anxious condition. The analysis strategy was carried out using SPSS version 23.

## **Results**

### **Repeated-measures data**

(Please see Appendix L for independent groups data and analysis.)

### **Parametric Assumptions Check**

Data was checked for skewness, kurtosis, normality of distribution and homogeneity of variance. All data was adequately normally distributed apart from paranoia after the anxious condition. An extreme outlier that was more than three standard deviations below the mean for this variable was excluded from further statistical analyses, resulting in adequately normally distributed data for this variable.

### **Order Effects Check**

A mixed-model 2 x 2 ANOVA with between-subjects factor 'randomisation order' (anxious first, neutral first) and within-subjects factor 'time' (pre, post) was carried out with each variable of interest as the dependent variable. The results were examined for significant interactions between randomisation order and time to see if there were order-effects, despite

counterbalancing. No significant interactions were found for any variable apart from paranoia distress in the neutral condition where there was a significant time x randomization interaction,  $F(1, 20) = 5.05, p = .036$ . This shows that paranoia distress ratings were different in the neutral condition depending on which condition participants were randomised to experience first. Independent t-tests showed that paranoia distress was the same before the neutral condition for the anxious first ( $M = 3.55$ ;  $SD = 3.05$ ) and neutral first ( $M = 3.55$ ;  $SD = 3.58$ ) participants;  $t(20) = .0, p = 1$ . However, after the neutral condition, people who were randomised to have the anxious condition first had significantly less paranoia distress ( $M = 1.31$ ;  $SD = 2$ ) than those who had the neutral condition first ( $M = 4.15$ ;  $SD = 3.36$ );  $t(16.28) = 2.41, p = .028$ . The neutral condition may have reduced paranoia distress in those who were already familiar with the protocol. Due to these carryover-effects paranoia distress was not included in further analyses.

### Manipulation Check

Results of the repeated measures ANOVAs, and t-tests investigating significant interactions are shown in Table 3.2.

Table 3.2

*2 (Time) x 2 (Condition) Repeated Measures ANOVA Results and Post-hoc t-test Results.*

Variable	Time	Condition	Time x condition	<i>t test</i> T1 (N vs A)	<i>t test</i> T2 (N vs A)
<b>Anxiety</b>	$F(1, 21) = 21.55,$ $p < .001^{***}$	$F(1, 21) = 39.39,$ $p < .001^{***}$	$F(1, 21) = 66.29,$ $p < .001^{***}$	$t(21) = -.33;$ $p = .75$	$t(21) = -10.8;$ $p < .001^{***}$
<b>Positive-Affect</b>	$F(1, 21) = 10.63,$ $p = .004^{**}$	$F(1, 21) = 33.7,$ $p < .001^{***}$	$F(1, 21) = 20.78,$ $p < .001^{***}$	$t(21) = 1.24;$ $p = .23$	$t(21) = 6.66;$ $p < .001^{***}$
<b>Negative-Affect</b>	$F(1, 21) = 20.65,$ $p < .001^{***}$	$F(1, 21) = 17.01,$ $p < .001^{***}$	$F(1, 21) = 39.24,$ $p < .001^{***}$	$t(21) = -.26;$ $p = .8$	$t(21) = -6.95;$ $p < .001^{***}$
<b>Paranoia</b>	$F(1, 20) = 4.25,$ $p = .052^*$	$F(1, 20) = 14.31,$ $p = .001^{**}$	$F(1, 20) = 18.73,$ $p < .001^{***}$	$t(21) = -.42;$ $p = .67$	$t(20) = -5.56;$ $p < .001^{***}$

*Note: T1=pre-condition; T2=post-condition; N vs A=neutral versus anxious; \*=significant at .05 level; \*\*=significant at .01 level; \*\*\*=significant at .001 level*

There were no significant differences between conditions at baseline (T1). Anxiety, negative-affect, and paranoia were significantly higher, and positive-affect significantly lower, after the anxious condition compared to the neutral condition (T2). This confirmed that the anxious-condition was effective at increasing anxiety. Figures 3.1 and 3.2 provide a visual depiction of how anxiety and paranoia ratings changed from pre-to-post each condition.

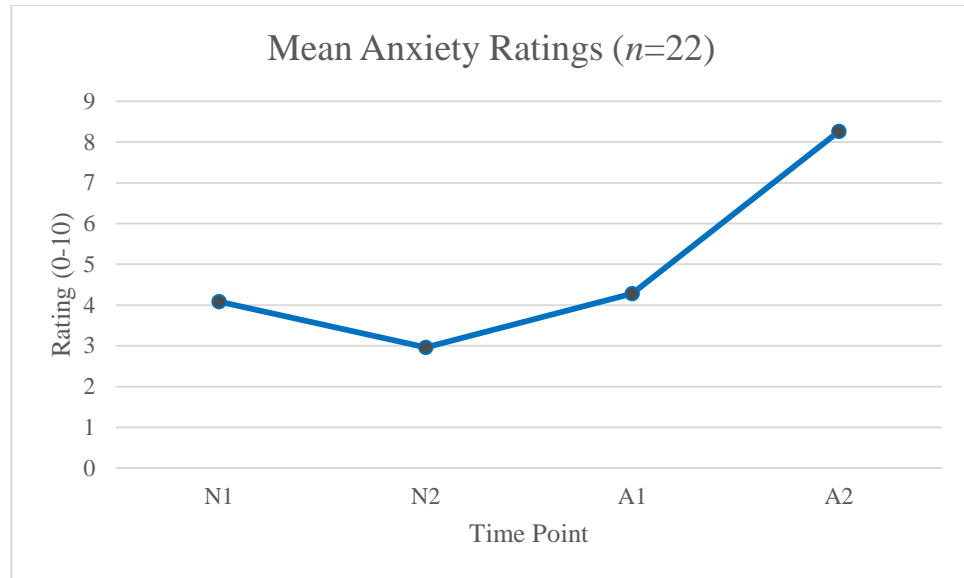


Figure 3.1. Mean Anxiety Ratings at each Time Point. (N1 = pre-neutral condition; N2 = post-neutral condition; A1 = pre-anxious condition; A2 = post-anxious condition)

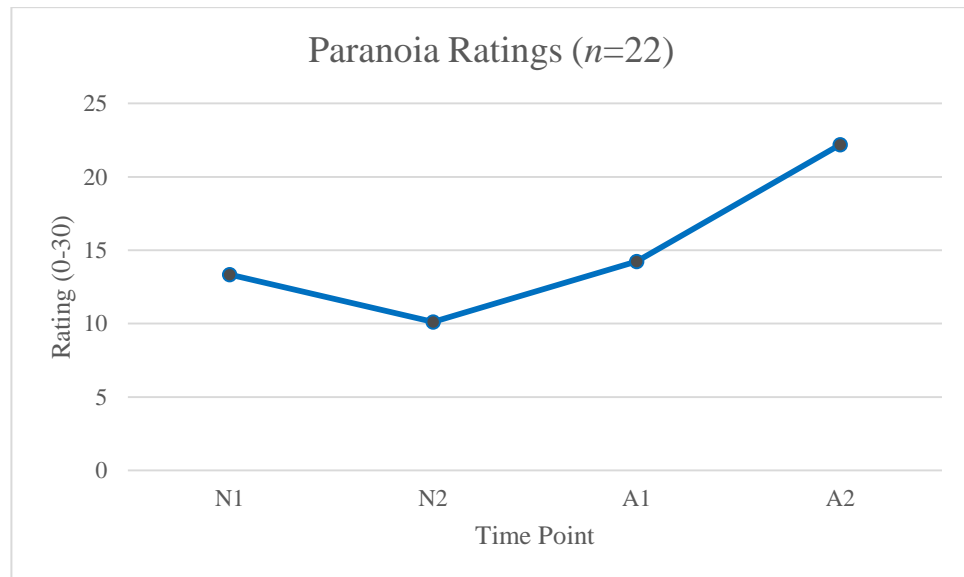


Figure 3.2. Mean Paranoia Ratings at each Time Point. (N1 = pre-neutral condition; N2 = post-neutral condition; A1 = pre-anxious condition; A2 = post-anxious condition)

### Hypothesis One: Effect of Anxious Condition on Paranoia

To check if these differences were due to changes from pre-to-post the anxious or the neutral condition, paired t-tests were conducted (Table 3.3).

Table 3.3

*Paired t-test Results for Pre-to-Post Condition Scores*

<b>Variable Condition</b>	<b>Pre - Post Rating: M (SD)</b>	<b>Difference: M (SD)</b>	<b>N</b>	<b><i>t</i></b>	<b><i>p</i></b>	<b><i>d</i></b>
<b>Paranoia</b>						
<i>Neutral</i>	13.35 (8.83) – 10.12 (8.33)	3.23 (6.3)	21	2.35	.029*	0.37
<i>Anxious</i>	14.24 (8.38) – 22.19 (6.42)	-7.94 (9.23)	21	-3.95	.001***	1.07
<b>Anxiety</b>						
<i>Neutral</i>	4.09 (2.76) – 2.96 (2.2)	1.13 (1.88)	22	2.81	.011**	0.45
<i>Anxious</i>	4.28 (2.57) – 8.26 (1.72)	-3.98 (2.22)	22	-8.39	<.001***	1.82
<b>Negative</b>						
<i>Neutral</i>	3.25 (2.64) – 2.92 (1.36)	.32 (1.89)	22	.8	.43	0.16
<i>Anxious</i>	3.4 (2.65) – 6.81 (2.65)	-3.41 (2.32)	22	-6.88	<.001***	1.29
<b>Positive</b>						
<i>Neutral</i>	5.02 (3.18) – 5.6 (3.07)	-.58 (2.65)	22	-1.03	.315	0.19
<i>Anxious</i>	4.46 (2.77) – 1.81 (2)	2.65 (1.7)	22	7.32	<.001***	1.1

*Note: M=mean; SD=standard deviation; \*=significant at .05 level; \*\*=significant at .01 level; \*\*\*=significant at .001 level. Effect size indicated by Cohen's *d*, where 0.2 = small, 0.5 = medium, and 0.8 = large.*

The results showed that there was a significant increase in anxiety, negative-affect and paranoia, and a significant decrease in positive-affect, from pre-to-post the anxious-condition. There was also a significant decrease in anxiety and paranoia from pre-to-post the neutral condition. This confirms hypothesis one, the anxious-condition led to more state-paranoia than the neutral condition.

Although the anxious condition increased anxiety, it also significantly increased negative-affect and reduced positive-affect. For this reason, the relationship between these variables and levels of paranoia after the anxious condition was explored.

### **Hypothesis Two: State-Anxiety will Predict State-Paranoia**

Simple linear regression showed that state-anxiety after the anxious condition was a significant predictor of state-paranoia after the anxious condition,  $R^2 = .31$ ,  $F(1, 19) = 8.41$ ,  $p$

= .009, (Table 3.4). This supports hypothesis two, state-anxiety was a significant predictor of state-paranoia.

### Hypothesis Three: State-Anxiety as a Unique Predictor of State-Paranoia

Negative-affect after the anxious condition was a significant predictor of state-paranoia after the anxious condition,  $R^2 = .39$ ,  $F(1, 19) = 12.28$ ,  $p = .002$ . Positive-affect was not a significant predictor,  $R^2 = .17$ ,  $F(1, 19) = 4.01$ ,  $p = .06$ .

Multiple regression (Method: ENTER) was used to ascertain if anxiety still significantly predicted paranoia when the variance accounted for by negative-affect was taken into account (Table 3.4). Together, the two variables predicted 48% of the variance in paranoia,  $R^2 = .48$ ,  $F(2, 18) = 8.38$ ,  $p = .003$ . However anxiety no longer significantly predicted paranoia when negative-affect was included,  $\beta = .34$ ,  $t = 1.77$ ,  $p = .094$ , but negative-affect remained a significant predictor,  $\beta = .47$ ,  $t = 2.47$ ,  $p = .024$ . Hypothesis three was not supported; negative-affect, rather than anxiety, was a unique predictor of paranoia after the anxiety induction.

Table 3.4

*Regression Results for Predictors of Paranoia post the Anxiety Induction (n = 21)*

Predictor variable	<i>b</i>	Std Error	$\beta$	<i>p</i>	$R^2$	$f^2$
<b>Constant</b>	3.8	6.45		<..001***		
<b>AnxietyT2A</b>	2.19	.75	.55	.009**	.31	.45
<b>Constant</b>	9.99	3.66		<..001***		
<b>NegativeAffectT2A</b>	1.72	.49	.63	.002**	.39	.64
<b>Constant</b>	24.55	1.76		<..001***		
<b>PositiveAffectT2A</b>	-1.43	.71	-.42	.06	.17	.2
<b>Constant</b>	1.81	5.79		.007**		
<b>AnxietyT2A</b>	1.33	.75	.34	.094	.48	.92
<b>NegativeAffectT2A</b>	1.29	.52	.47	.024*		

*Note: 'T2A'=post anxiety condition; 'Std' = standard; \*=significant at .05 level;*

*\*\*=significant at .01 level*

### Hypothesis Four: The Relationship between Trait-Paranoia and State-Paranoia

Regression analyses showed trait paranoia as measured by the PSYRATS-B was a significant predictor of state-paranoia after the anxious-mood condition. Trait-paranoia did not predict state-paranoia before or after the neutral-mood condition or before the anxious-mood condition (Table 3.5). This supports hypothesis four, suggesting that people with higher trait-paranoia are more sensitive to the impact of fluctuations in affect on levels of state-paranoia.

Table 3.5

*Regression Results for Trait-Paranoia as a Predictor of State-Paranoia (n = 21)*

Dependent Variable	Predictor Variable	<i>b</i>	Standard Error	$\beta$	<i>p</i>	$R^2$	$f^2$
<b>State-Anxiety N1</b>	Constant	-.24	10.82		.98		
	PSYRATS-B	.77	.64	.26	.24	.07	0.08
<b>State-Anxiety N2</b>	Constant	-2.27	10.03		.82		
	PSYRATS-B	.71	.59	.26	.24	.07	0.08
<b>State-Anxiety A1</b>	Constant	-.01	10.32		1		
	PSYRATS-B	.81	.61	.29	.2	.08	0.09
<b>State-Anxiety A2</b>	Constant	1.43	8.59		.87		
	PSYRATS-B	1.18	.5	.46	.03*	.21	0.27

*Note: N = neutral condition; A = anxious condition; 1 = pre; 2 = post; \* = significant at the .05 level*

### Discussion

This experimental study set out to investigate the role of state-anxiety in state-paranoia in people experiencing paranoid delusions in the context of a psychosis-spectrum diagnosis. To the authors' knowledge, it was the first study to attempt to directly manipulate anxiety in people with paranoia in the context of clinical psychosis.

The first hypothesis; that the anxious-mood induction would lead to greater state-paranoia than the neutral-mood induction, was supported. The second hypothesis; that state-paranoia would be predicted by state-anxiety after the anxious condition, was supported. The

third hypothesis, that state-anxiety would predict state-paranoia to a greater extent than other affective states after the anxious condition, was not supported. The anxious-mood induction significantly increased anxiety but also significantly increased negative-affect and decreased positive-affect. Results showed that whilst level of anxiety predicted paranoia, negative-affect was also a significant predictor of paranoia, over and above anxiety. The fourth hypothesis, that higher trait-paranoia would predict higher state-paranoia after the anxious-mood induction, was supported.

## **Implications**

### **Theory and Research**

This study confirmed findings that -affect is linked to paranoia in clinically paranoid samples (Bosanac et al., 2016; R. J. Drake et al., 2004; Freeman et al., 2010; Hartley et al., 2013; Thewissen et al., 2011). By directly manipulating anxiety, this study has demonstrated that anxiety appears to be causally implicated in paranoia, rather than being a consequence of it.

The study question was ‘does state-anxiety predict state-paranoia *to a greater extent than other factors*’ and this study found the answer to be, ‘no’. Negative affect was a unique significant predictor of paranoia when included in a model with anxiety. However, this finding does not contradict the threat-anticipation model of paranoia. Although the model affords anxiety a key role in delusion maintenance, it also posits that anxiety interacts with negative-affect, reasoning biases, safety behaviours, anomalous experiences and previous life experiences (Freeman, 2007). It may be that anxiety is necessary for state-paranoia to be triggered but that negative affect, at least in populations experiencing clinical paranoia, can play a more crucial role.

Lincoln and colleague’s (2010) contradictory findings, that anxiety *was* a unique predictor of paranoia when included in a model with negative affect, were found in a non-clinical population. It is feasible that anxiety is a unique predictor for state-paranoia in non-clinical populations but that once paranoia has reached clinically relevant levels, it is maintained in a different way, as suggested by the results of the present study. This would make sense given that the threat-anticipation model offers a separate formulation for the formation versus the maintenance of paranoia. As a non-clinical sample, participants in



Lincoln and colleague's (2010) study were less likely than patients in the present study to have experienced anomalous experiences and past trauma, proposed by the model to lead to clinically significant paranoid delusions. Therefore, anxiety may have had a bigger impact compared to other factors in their study than perhaps it would in clinical groups. Feeling state-negative-affect may be less triggering of state-paranoia for someone who has not faced the stigma, shame and depression often inherent in having a diagnosis of psychosis or seeking help. Interestingly, the measure of affect used in this study included shame, which may have contributed to the strong links found between negative affect and paranoia. Indeed, a recent study in a non-clinical population found that negative self-evaluations were associated with state-paranoia (Stewart et al., 2017).

The finding that trait-paranoia was predictive of state-paranoia after the anxious-mood induction fits with other research showing that anxiety has a greater impact on psychotic phenomena in people with higher baseline symptomology (Kesting, Bredenpohl, Klenke, Westermann, & Lincoln, 2013; Lincoln et al., 2010; Lincoln, Peter, Schäfer, & Moritz, 2009). The finding that baseline paranoia *did not* predict state-paranoia at any time point other than after the anxious-condition supports the threat-anticipation model of paranoia, showing that a higher level of trait paranoia does not mean higher levels of state-paranoia unless other relevant factors are present (e.g. changes in affect).

### **Clinical**

Although more rigorous research is needed to corroborate that state-anxiety and state-negative-affect play a causal role in state-paranoia in clinical samples, the results of this study imply that interventions for emotion regulation could be beneficial. There is emerging evidence that interventions for anxiety and worry can help to reduce trait paranoia (Foster et al., 2010; Freeman et al., 2015). Based on the findings of this study, it may be that basic emotion regulation skills could be useful as tools to manage state-paranoia. For example, relaxing breathing, attention training, progressive muscle relaxation and compassionate imagery are all simple techniques that could be delivered at a low cost by most healthcare professionals to provide coping mechanisms for this population.

Interestingly, the neutral-mood induction in this study led to significant decreases in paranoia and anxiety. This is in line with findings that imagining a neutral object in detail can

lead to reductions in paranoia and negative-affect in clinically paranoid populations (Ascone et al., 2016). It is likely that the attentional capacity needed to conjure up imagery in sensory detail allows attention to be diverted from other potentially distressing stimuli. Distraction has been found to effectively reduce state-anxiety in people with a psychosis-spectrum diagnosis (Grezellschak, Lincoln, & Westermann, 2015). Further research could look to simple intervention strategies that involve attentional capacity to see if these are found to be effective at reducing negative-affect and paranoia in clinical settings.

### **Strengths and Limitations**

Most research looking at the links between affect and paranoia is either correlational in nature or based on non-clinical samples. This study used an experimental design with a clinical population. The implication of causality between affect and state-paranoia lends stronger evidence to psychological models of paranoia than correlational data and has implications for further theoretical and clinical research, as outlined above. Clinical paranoia is theorised to have some differences to non-clinical paranoia, despite being part of the same spectrum. It is hoped that the engagement of clinically paranoid participants will encourage other researchers to conduct experimental studies with this population.

Power calculations indicated that this study had adequate power to detect significant outcomes for the majority of statistical analyses (Appendix K). However, the study was underpowered to detect changes in variables from pre-to-post in the neutral condition or to detect a significant regression effect of positive-affect on paranoia. Therefore, more participants would be needed to confidently extrapolate the findings of these analyses to populations of people experiencing clinical paranoia in the context of psychosis. Furthermore, the sample size was too small to control for other factors that may have impacted on anxiety and paranoia, such as medication and substance use.

A repeated-measures crossover design with counter-balancing was used due to issues with recruiting enough participants to power an independent groups design. Both conditions were conducted on the same day, which risked carry-over effects. Counterbalancing controlled this for most variables, but order-effects were present for paranoia-distress, meaning that this variable of interest could not be further explored. Future studies would ideally replicate with an independent groups design and a larger sample size.

In future studies, it would be preferable to use a validated brief measure of affect without adjusting it, especially given the variance in internal-reliability that was found in the sub-scales used in this study. However, as this study was interested in looking at anxiety separately from other types of affect, many pre-existing brief measures were not suitable. Single-item measures (e.g. 'I feel angry') have been used to explore affect and paranoia in this population before (Thewissen et al., 2011) and may have been preferable to modified measures. Physiological measures of anxiety such as heart rate or galvanic skin response (Guinot Jimeno, Yuste Bielsa, Cuadros Fernandez, Lorente Rodriguez, & Mercade Bellido, 2011) would be a helpful addition to future research to clarify if self-reported anxiety was congruent with more objective measures.

The anxious-memory recall manipulation was chosen as other studies have found this to lead to increases in anxiety in this population (Ascone et al., 2016; Lincoln et al., 2010). As it was a memory that the participants had already experienced and coped with, it was felt to be a task that this population could undergo with minimal chance of adverse effects and that would mimic 'real-world' anxiety. However, given the semi-ideographic nature of such a manipulation, it was not possible to ensure that the condition was matched across participants. Chosen memories may have involved affect other than anxiety, as indicated by the observed increases in negative-affect and decreases in positive-affect. In future research, a different mood induction more specific to anxious-mood, and that could be the same for each participant, would be useful to investigate this further. Examples of this include anxiety-invoking music (e.g. Grant & Stewart, 2007) and unsolvable puzzles (e.g. Habhab, Sheldon, & Loeb, 2009).

## **Future Directions**

Further research is needed to delineate the unique and interacting effects of different types of affect, and other factors such as reasoning biases, predisposition to anomalous experiences, safety behaviours and previous life experiences, in the maintenance of clinical paranoia. Based on the findings of this study it could be particularly interesting to look at shame, anger and sadness as individual components of negative affect. Much of the experimental research to date has been conducted in non-clinical groups. Experimental studies in clinically paranoid populations can help to advance theories of paranoia formation and

maintenance, and inform interventions. It would be particularly interesting to further explore triggers of state-paranoia to elucidate possible targets for developing coping strategies. Brief interventions for state-paranoia may present a more targeted and efficient alternative to current CBT approaches for delusions and be less demanding on services.

The conflicting findings of this study in a clinical population with Lincoln and colleague's (2010) findings in a non-clinical population requires further investigation. Studies that seek to untangle the relationship between negative-affect, anxiety and paranoia in both at-risk and clinical groups can help highlight which factors can be most usefully targeted to help with the prevention and management of paranoia. Future studies would benefit from addressing the methodological limitations outlined in this paper.

## **Conclusions**

In summary, this was the first study to directly manipulate anxiety in order to explore its impact on state-paranoia in a population of people experiencing clinically significant psychosis. This study found that state-paranoia was higher after an anxious-mood induction and that this was predicted by levels of state-anxiety and negative-affect. Negative-affect was a unique predictor when both were taken into account. Trait paranoia was also shown to predict levels of state-paranoia after the anxious mood-induction, indicating that vulnerability to paranoia makes it more likely that changes in affective states will trigger state-paranoia. Although these findings need to be interpreted with caution due to methodological limitations, they highlight some interesting avenues for further research.

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## Executive Summary

Paranoid delusions can be a particularly distressing experience that are reported by 70% of people with a first episode of psychosis as well as by people with other diagnoses and non-clinical populations. The threat-anticipation model of paranoia posits that paranoia develops as a way to make sense of unusual experiences. This model suggests that an interaction of vulnerabilities (e.g. trauma, deprivation), anomalous experiences (e.g. distorted perception, hallucinations), affective processes (e.g. anxiety, depression), reasoning biases (e.g. jumping to conclusions, confirmatory bias) and safety behaviours (e.g. withdrawal from others, vigilance for threat) lead to and maintain paranoid ideation.

The threat-anticipation model affords anxiety a key role in paranoia. Anxiety occurs when we perceive something as threatening, and paranoid delusions involve a belief that harm is, or will be, purposefully inflicted on the individual. Therefore it makes intuitive sense that anxiety would be involved in the formation and maintenance of paranoia. There is strong evidence to suggest that anxiety is *associated* with paranoia in clinical and non-clinical samples. However, no research to date has directly manipulated anxiety to investigate if state-anxiety has a *causal* role in state-paranoia in clinical populations.

In this experimental study, an anxious-mood induction was compared to a neutral - mood induction to see whether purposefully increasing levels of state-anxiety led to increased levels of state-paranoia in people experiencing psychosis. The study was interested in whether state-anxiety predicted paranoia to a greater extent than other possible predictors measured in the study. The study also explored whether trait-paranoia predicted state-paranoia after the anxious condition.

Twenty-two people experiencing paranoia in the context of clinically significant psychosis took part in the study. The study used a repeated-measures design, meaning that all participants took part in both conditions. Participants were asked to fill in some baseline measures and then asked to recall a recent anxiety-provoking memory. Before and after this they filled in a questionnaire measuring their feelings and paranoid thoughts in that moment. After a break participants were asked to recall a recent neutral-memory, for example an activity they perform every day. They also filled in the same questionnaire before and after recalling this memory. Half of the participants recalled the neutral-memory first to counterbalance any order effects.

Results showed that state-paranoia was significantly higher after the anxious-mood induction and that this was predicted by levels of state-anxiety, as hypothesised. However, negative-affect was also a significant predictor of state-paranoia. When both state-anxiety and negative-affect were included in the statistical analysis at the same time, only negative-affect was a significant predictor. This did not support the prediction that state-anxiety would be the strongest predictor of state-paranoia. Findings confirmed that trait-levels of paranoia predicted state-levels of paranoia after the anxious-mood induction.

There were a number of limitations in the study. The initial plan was to conduct an independent groups design, which was not possible. The repeated-measures design is not ideal given the potential for carry-over effects, which were seen in this study with paranoia-related distress. Alternative measures of affect, including physiological measures, may have been preferable to the amended measure that was used in this study. Furthermore, an anxious-mood induction that was identical between participants would have allowed better consistency and reduced the likelihood of other types of affect being stimulated.

Strengths included the novel approach of the study in directly manipulating anxiety in people experiencing paranoia in the context of clinically significant psychosis. The study findings were different from a similar study in a non-clinical population, raising important questions about differences between these populations in terms of the factors involved in paranoid ideation. The study provided evidence that anxiety and negative-affect are causally involved in state-paranoia, rather than being a consequence of it. The findings also supported the idea that vulnerability to paranoia (e.g. trait-paranoia) increases sensitivity to the effects of affect on state-paranoia.

Given the small sample size of this study, further research is needed to clarify and extend the findings, including the relationship between negative-affect and anxiety in the maintenance of paranoia. Further experimental research with clinical populations is needed. These initial findings suggest that interventions to target negative-affect may be beneficial for coping with and reducing state-paranoia. Interestingly, the neutral-mood induction was found to reduce state-anxiety and state-paranoia, suggesting the interventions involving distraction or attention training could be beneficial. Although these findings need to be interpreted with caution due to methodological limitations, they highlight some interesting avenues for further research.

### **Connecting Narrative**

Having held both a Research Health Psychologist and a Research Assistant post after graduating from my Philosophy & Psychology undergraduate degree, I felt I understood research design and recruitment issues well. However, I found the research components of the University of Bath DClinPsy course to be far more challenging than I had anticipated and most definitely the most stress-inducing part of the training.

### **Case Studies**

Clinical work is the key reason that people decide to become Clinical Psychologists and I found the case-studies to be particularly rewarding pieces of work. The case-studies offered space to think about theory-practice links within my clinical work and I noticed that I was more diligent about keeping ‘on model’ when I was planning to write up a case. Having to complete two single-case experimental designs impressed the importance of evaluating our work with clients in a more formal way, whether with validated outcome measures or with ideographic measures. For example, my third case-study looking at identifying, assessing and treating post-traumatic stress disorder (PTSD) in adolescents involved using a diagnosis-based outcome measure. Checking this each week meant I was constantly orientated to which problems were reducing and which remained elevated, meaning I could better target my therapeutic interventions. Having this case-study published has encouraged me to use routine outcome measures in my clinical work more often, keeping my scientist-practitioner focus and enabling me to more easily publish cases that turn out to be clinically or theoretically interesting.

I have also enjoyed using the case-studies to explore more creative clinical work. For example, my first case-study looked at using diagnosis-specific cognitive behavioural therapy (CBT) as a stepping stone to transdiagnostic CBT. Through publication I was able to share this method of working with other clinicians and hopefully offer this format as a possible avenue for work with similar ‘complex’ cases. In my fifth case-study I used a reflective format to explore boundaries when working with asylum seekers. This reminded me that research exploring our human-experience of therapy can be just as valuable as outcome-based research. It showed me how reflective case-studies can keep us questioning, and being accountable for, our own clinical decision-making.

I believe the case-study format of research has the potential for inspiring new avenues of enquiry and offering ideas for other clinicians to contemplate in their work. For this reason I included three brief case-study examples to support my conceptual literature review.

### **Critical Review of the Literature**

I have a particular interest area in trauma and decided to pursue a literature review in this area to afford me the opportunity to immerse myself in trauma-relevant literature. I was particularly interested in how cumulative traumas may impact the individual differently than a single-event trauma. In my exploration, I came across the idea of poly-victimisation. I was excited to see that other researchers were considering the impact of having a number of different types of trauma. I was also interested to see this moving beyond trauma and into the idea of victimisation, including a number of experiences that would not meet criteria for trauma but undoubtedly can have lasting psychological effects on an individual. I liaised with Dr. Catherine Hamilton-Giachritsis who has looked at cumulative trauma, multiple traumas and poly-victimisation in her work. Having recently spent a day at a forensic adolescent inpatient ward I was particularly interested in the role of poly-victimisation in youth offending.

We designed a systematic review of the literature to explore rates of poly-victimisation in juvenile offenders and what factors this correlated with, such as PTSD, offending history, self-harm and so forth. I put a lot of work into picking search terms, designing data extraction protocols, reading relevant papers, following PRISMA guidance and writing an introduction. However, due to the different ways poly-victimisation has been described it was hard to define and search results were in the thousands.

At the same time, I had started my placement in a community learning disability team. A number of service-users I was working with were clearly managing the effects of trauma. On consultation with the team, it became apparent that staff were not aware of or confident in approaches to intervening with PTSD in people with learning disabilities (PWLD). A perusal of the literature showed me that the evidence-base was sparse and that there were ethical concerns around some interventions, such as informed consent for potentially distressing therapeutic techniques. I began to apply compassion-focused therapy (CFT) techniques with the service-users I was working with to try and alleviate some of their distress. I was

impressed by how successful some of the interventions were and looked to the research in the field to think about why this might be. My personal interest and passion for addressing this gap in services that are available for PWLD led me to my literature review. Although it was hard to let go of the one I had worked so hard on already, it was great to write something that I felt had some immediate clinical relevance.

The process of writing the conceptual review was daunting. I was nervous that a conceptual review might not meet the demands of the doctorate and so included an incredibly detailed review of trauma in PWLD. This took up my whole word count. Reassurance from Dr. Cathy Randle-Phillips, my internal supervisor, that conceptual reviews had been undertaken on the course before enabled me to significantly reduce this review. Dr. Cathy Randle-Phillips is a clinician in LD and was incredibly encouraging about the value and need for such work to address the gaps in the LD literature. The literature behind CFT is vast and I initially got sucked into lots of detail. On showing an initial draft to a colleague working in LD, she suggested I simplify the section on CFT to make it more accessible to clinicians, and include my brief case study examples. Modifying the conceptual review in this way helped me feel more confident that the paper had heuristic value. Dr. Andrew Medley, my external supervisor, conducts research in CFT approaches and was able to guide me as to what parts were important to keep in and what parts could be removed.

After submitting for publication, initial feedback was that the review should be amended to talk about CFT for LD more generally, rather than specifying it as a target for trauma. We plan to edit the literature review accordingly, making it shorter in the process. However, for the purposes of the DClinPsy, and being true to the roots of how the paper was inspired, I chose to leave it in its original form. I am considering writing up a separate paper based on the introduction as a ‘call to arms’ for more creative trauma work in LD in order to develop more options for this population and address the lack of LD-specific NICE guidelines for trauma.

Writing the literature review was inspired by my experiences on placement and my awareness that service-user needs may not be being met, similarly to my service improvement project.

## **Service Improvement Project**

I had two service improvement project ideas that struggled to get off the ground. The first was planned to assess a service-user group for men with a first episode of psychosis and see if generated recommendations led to improvements in service-user ratings and attendance. However, the group did not consent to taking part in the project after one member became worried that it was part of a government conspiracy. I had not met the group yet and in hindsight think I should have met them myself to explain the project rather than asking a member of staff to seek consent before they knew who I was.

The second planned project was inspired by our systemic training, which had stressed the importance of involving the system around an individual in their support where appropriate. I arranged with the North Somerset Improving Access to Psychological Therapies (IAPT) team to come and run some focus groups with the carer groups that they ran to ascertain what the facilitators and barriers were to being involved in the care of their loved one and their views of the group. We planned to take this data and make recommendations for the groups and then compare outcome scores for the six-months after these were implemented to the six-months before to see if there was any improvement. As the IAPT service regularly collect outcome data this would be particularly easy to record. However, the IAPT service was incredibly busy and after eight-weeks of phoning and emailing with no response, I realised that by the time I did manage to get through to them it would be a long time before the focus groups were arranged.

I then turned my attentions to my neurology placement. I was aware that I was working in a well-funded, 'gold-standard' service that supported people at home after having a stroke. It was clear the team had a passion for meeting the needs of their service-users and recovery rates were good. However, there had been no formal evaluations of how service-users viewed the team and, as such, service developments were based largely on staff and stake-holder views. The team managers approached me to see if I would be happy to undertake a qualitative project looking at service-user views. Given the importance of unpaid carers in supporting stroke survivors, we included carers in the interviews too. It was a large task to identify every eligible patient and carer based on our criteria and I spent many days looking through databases. In the future, I would ensure I had an assistant to help reduce the burden of the

initial screening. Conducting the interviews was really enjoyable, as was coding for themes. It was a long time since I had conducted any qualitative research and I enjoyed the intense nature of becoming immersed in the data. It was challenging to reduce all of the codes down into themes as the data was so rich. I asked an assistant to be my second coder and it was very helpful having someone else to corroborate or challenge my ideas, bringing more critical awareness to the process.

It was exciting to get the service improvement project published, although in a much-reduced format. I put a lot of work into devising and actioning recommendations that the team could implement within budget. The team reported feeling more motivated to incorporate recommendations into their working practice knowing that they had come from service-users. It was particularly useful thinking about nation-wide recommendations. Appreciating that this was a well-resourced service, it was important to think of key messages for managers in other localities and how the data might relate to their services. I also hoped that the paper might help other services to make a case to commissioners for funding given, for example, our finding that integrated psychology and psychologically-informed staff were highlighted as a particularly valuable part of the service.

I really valued working with a service and its users to undertake research that directly led to change and hope to incorporate smaller-scale service improvement projects into my future career. It was also particularly helpful running two pilot interviews to get feedback on the interview procedure and questions. Service-user feedback was also instrumental in the design of my main research project.

### **Main Research Project**

I wanted my main research project to focus on the experience of psychosis as this is an area I had always been interested in but had not had the chance to work with clinically. I had been inspired by Dr. Dan Freeman when attending his talks at the University Oxford in a previous job. It felt intuitive that psychosis was on a spectrum with more every day experiences rather than being some categorically ‘other’ position. I initially began looking at conducting some research into self-stigma or shame in this population but struggled to find a research study that was clearly indicated by the existing literature and could be completed within the constraints of a DClinPsy. I had been building an interest in CFT since attending



some training with Dr. Paul Gilbert and wondered if I could investigate CFT approaches to psychosis.

I became particularly interested in paranoia due to its overlap with anxious worries, something I was working with frequently in my clinical practice. I originally sought to do a small pilot randomised control trial in people experiencing paranoia in the context of psychosis with 12 people receiving a brief four-week CFT intervention focusing on formulation and imagery, and 12 people receiving treatment as usual. This was similar to a pilot carried out for a worry intervention in the same population. However, I was told by the course that this was too ambitious for a DClinPsy project and I was advised to stick to a one-session experimental study. I then explored using compassion-focused imagery versus neutral imagery for paranoia but knew I would be underpowered to detect a difference between groups as a previous study in a similar field had needed 54 per group. In the end, after lots of reading and researching, I realised that the link between anxiety and paranoia had never been experimentally tested in a clinical population. I had presumed this had been done given the extensive literature about anxiety and paranoia. I decided to investigate this myself, including compassion-focused imagery as the relaxation technique to allow some exploratory data around this intervention to be analysed in a separate paper.

It took a long time to develop the study protocol as I deliberated over semi-ideographic versus standardised anxiety-inductions and which measures to use to delineate different types of affect. I knew the IRAS ethics approval process was notoriously slow and it had recently changed, meaning ‘hiccups’ in the new system were yet to be ironed out. I was informed by previous trainees that recruitment from this population had been hard and that attrition was an issue. Based on these conversations, I decided to use a design where both independent groups and repeated measures data could be used depending on how many people were recruited. I was advised that other researchers had found it hard to conduct follow-up visits and I should keep my repeated measures on the same day. In retrospect, this was not a wise move as it may not have allowed sufficient time for condition-one effects to have diminished, something that I did not fully appreciate at the time. Had I had more ‘thinking-space’ I believe the study would have been better thought out. However, I received some very helpful feedback from a service-user that I piloted the study with that influenced which measures were used and other elements

of the design. I am keen to liaise with service-users at the development stage of research in the future.

Recruitment, as expected, was incredibly hard. I spent all day, every day in Summer 2016 recruiting and did not receive a single referral until October, four-months after I had received full ethical clearance. My two other colleagues conducting research with this population received ethical clearance many months after I did and had two other experimental groups to recruit to. In order to ease their burden, I had obtained ethical approval to ask for consent to pass my participants' details on to the other researchers. This was a good way to reduce the demands we were placing on local teams as a course and to pool resources, but meant I felt the added weight on my shoulders of understanding, representing and recruiting for the three projects. Added to this was the inability of many teams to keep our projects in mind given their highly demanding jobs. This meant that many eligible service-users were not finding out about the project. To address this I paid for a mail-out to 200 people identified by the R&D team as potentially eligible but only received two responses.

The realities of carrying out research in the NHS with hard to engage clients was brought home quite sharply by this experience. It was a shame that I did not have more time to design and conduct this research as I feel it was a worthwhile and interesting study. The time constraints and multiple demands inherent in a DClinPsy create a somewhat artificial research environment and I have tried to bear this in mind in order that I might be inspired to carry-out further experimental research in the future.

## **Summary**

In hindsight, I was unprepared for the demands of designing, recruiting, conducting and writing up research as a solo researcher. This is not to undermine the input from my supervisors, but having someone check your research proposal, recruitment progress, and write-up is not the same as co-working. All of my previous experience had been working as part of a large team on nationwide projects where decisions were made as a team and there were no strict time pressures. The time constraints of the course, as well as conducting the research alongside a full-time job, made it hard to give full attention to the details of each project, which could be incredibly stressful and demotivating.

Overall, I have found conducting the research extremely rewarding and have really valued the opportunity to explore different interest areas, rather than writing a large thesis on one topic. However, I do feel that the depth of knowledge writing a thesis can afford you is something I would have valued. It has been particularly valuable conducting a service improvement project where I saw my results feed directly into service change and incorporating service-user feedback into research design, which was not something I had done before. Writing up studies as journal articles has been excellent experience and has led some of my papers to be published, having been unpublished prior to the course.

I believe the course ethos has put me in a good position to continue my future career as a scientist-practitioner who is influenced by and seeks to influence the evidence-base. I particularly hope to engage in more clinically relevant research, such as case-studies and trials, as well as service-improvement projects and consultancies.

## **Acknowledgments**

First and foremost, I would like to express how indebted I am to my partner Jay for tolerating me through the ups and downs of completing the research. It would not have been possible to endure the pressure without his humour, warmth and constant belief in me. He encouraged me to keep going when I wanted to quit and reminded me to get out and dance when I was morphing into my desk. I look forward to being able to better give him all the patience and love he has given to me.

I have been fortunate to have two very supportive and passionate internal research supervisors for my three projects. I would like to thank Lorna Hogg for her optimistic and determined focus when my initial project ideas fell through. Lorna helped to refine my main research project write-up to make it much more accessible and kept encouraging me when I felt like giving up. I am grateful to Dr Cathy Randle-Phillips for helping me to develop and refine my skills with qualitative methodology and inspiring my passion around advocating for the rights of people with learning disabilities. Thanks to her reinforcement I took what felt like a brave step and wrote a conceptual literature review, which was extremely challenging and time-consuming but hugely rewarding. I thank Cathy for her guidance in the structure and development of the review. I am also thankful to Dr Andrew Medley who improved the accuracy and quality of the compassion-focused elements of the review and further enthused my interest in the area.

I would also like to thank all of my placement supervisors, Dr Jim Nightingale, Dr Leon Dych, Dr Jennifer Davis, Dr Sharon Davey, Dr Christina White, Dr Nadja Krohnert and Dr Mary Griggs. They supported me in completing the case studies and allowed me space to recruit and write-up my research studies when I needed it. Without their understanding and support I would have felt lost.

I would like to thank all of the participants who agreed to take part in my research and trusted me with their experiences. It was a real honour to be invited in to people's worlds and get to meet so many interesting and kind people. I would also like to thank all of the staff who engaged with my recruitment efforts and went out of their way to remember to invite participants into my study. It made a huge difference and was greatly appreciated.

I am also indebted to my good friend Lizzie Woodward who tirelessly helped me to understand SPSS, G\*Power and general statistics. Without her I would have drowned in my own panic.

Last but by no means least I would really like to extend a deep gratitude to my fellow trainees. Knowing you are not alone in your research struggles somehow makes them more manageable. I was humbled by how openly and honestly we all shared resources, worries and support with one another. It was an absolute pleasure to share this experience with them and I wish every single one of them the best in their future careers.

## Appendices

### Appendix A: Instructions for Authors - Journal of Applied Research in Intellectual Disabilities

#### 1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to

visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

#### 2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

##### 2.1 Authorship and Acknowledgements

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship. It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

**Acknowledgements:** Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source

of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

## **2.2 Ethical Approvals**

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 [www.wma.net](http://www.wma.net)) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

## **2.3 Clinical Trials**

Clinical trials should be reported using the CONSORT guidelines available at [www.consort-statement.org](http://www.consort-statement.org). A CONSORT checklist should also be included in the submission material ([www.consort-statement.org](http://www.consort-statement.org)).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: [www.clinicaltrials.org](http://www.clinicaltrials.org), [www.isrctn.org](http://www.isrctn.org). The clinical trial registration number and name of the trial register will then be published with the paper.

## **2.4 Conflict of Interest and Source of Funding**

**Conflict of Interest:** Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

**Source of Funding:** Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

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### **MANUSCRIPT TYPES ACCEPTED**

***Original Articles, Review Articles, Brief Reports, Book Reviews*** and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor.

Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.



## **Appendix B: Instructions for Authors – The Neuropsychologist**

Submissions which do not obviously fall into one of the categories below should be discussed with the Editor.

### **ARTICLES**

Submitted articles should be of relevance to neuropsychology or neuropsychological practice, and sent to the editorial team for refereeing. These could include guidelines for practice, the results of service evaluations, or debate about policy or practice. Reviewers will assess the article for clarity, economy of expression; its critical and analytical stance; and its originality.

Papers that are research oriented will be assessed for the usual criteria for academic rigour.

The editor or reviewer will communicate directly with the authors.

Papers should be as short as is consistent with clear presentation of subject matter, and will normally be 1,000-2,500 words in length. If you feel an article of over 2,500 word is justified then please state the reasons in an accompanying letter and this will be considered. Invited articles or papers will not necessarily be restricted to this word limit.

An abstract / summary of no more than 75 words should be provided at the beginning of the paper.

A policy of blind reviewing will be applied, so authors are requested not to put any personal information on the manuscript except at the head of the paper. This should be removable eg. as in a Word document. The editor will remove this prior to sending for review.

In the first instance, the Editor will read each submitted manuscript to see if it is appropriate to be considered for publication in The Neuropsychologist. If it is not, the author will be contacted and feedback given. If it is considered appropriate, the manuscript will be refereed by no more than two independent reviewers. The Editor will decide whether or not to publish the article in the light of the reports received. All papers will be evaluated by the Editor and refereed in terms of relevance, readability and interest.

### **GENERAL GUIDELINES**

General guidelines for refereed contributions should be submitted by email attaching a Word compatible document which is double spaced with wide margins. Footnotes should be avoided, and sheets should be numbered. A copy should be retained by the author.

All personal identification should appear on a front page which can be removed for refereeing purposes. Authors are requested to make sure that no personal identification appears elsewhere

in the manuscript. Please make sure that your contact information is correct at the time of submission. E-mail contact is preferred.

Tables should be on separate pages at the end of the document with clear indication in the text where they should be inserted. Each should have a self-explanatory title and should be comprehensible without reference to the text. They should be referred to in the text by Arabic numerals. Data given should be checked for accuracy and must agree with mentions in the text. Figures, i.e. diagrams, graphs or other illustrations should add new information to the article and should not duplicate information given elsewhere in a different form.

Any Figures that are hand drawn should be in camera-ready form, each on a separate sheet, numbered sequentially (Figure 1, etc.), and each identified on the back with the title of the paper. They should be carefully drawn, larger than their intended size. Captions should be listed on a separate sheet.

Bibliographical references in the text should quote the author's name and the date of publication thus: Williams (2002). They should be listed alphabetically by author at the end of the article according to APA style.

Proofs are sent to authors for the correction of print but not for the introduction of new or different material.

# How stroke patients and carers experience early supported discharge services: A qualitative study with recommendations for service development

Megan Cowles, Leon Dysch, Ellie Perry & Cathy Randle-Phillips

*Early supported discharge (ESD) services provide intensive, community rehabilitation for people after a stroke. This paper reports an evaluation of an ESD service from service-user perspectives using patient and carer interviews interpreted with thematic analysis. Recommendations are made about how the findings can inform meaningful service development in ESD teams. Elements identified as important for service-users are highlighted for consideration by ESD teams and commissioners.*

## Introduction

**S**TROKE is a major health problem in the UK with approximately 125,000 people having a stroke every year (NICE, 2013). Mortality and morbidity rates are high, with stroke being the fourth most common cause of death and the leading cause of complex disability in the UK (Stroke Association, 2015). NICE guidelines recommend Early Supported Discharge (ESD) services to provide intensive and specialist rehabilitation for stroke patients at home when they are able to transfer from bed to chair independently or with assistance of one person (NICE, 2013). ESD services provide a multidisciplinary approach in managing rehabilitation needs, supporting the physical, psychological, social and occupational goals of service users post-stroke.

This paper describes a service evaluation of an ESD team from service-user perspectives. The evaluation aimed to compare findings to previous studies, inform meaningful service development and to consider how results may be applicable to other ESD services. In the rest of this paper the term 'service-users' will be used to describe both patients and carers, with 'patients' or 'carers' being used to refer solely to the named group.

## Method

### *The service*

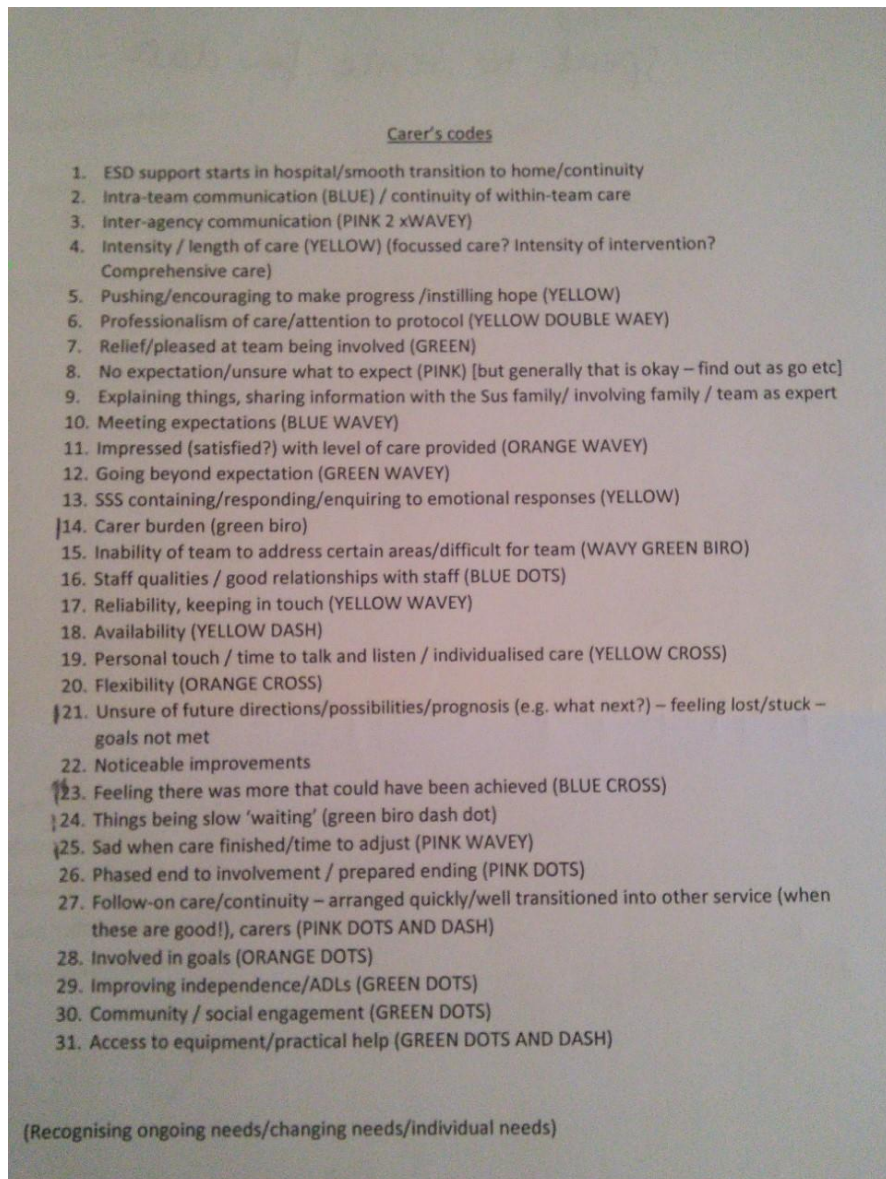
The ESD service evaluated is part of a community neurology and stroke service, alongside a planned rehabilitation service for people with long-term neurological conditions, and is commissioned by Bath and North East Somerset (BaNES) Clinical Commissioning Group. The ESD service in BaNES is a needs-based service set up to support those with intensive rehabilitation needs, which in most cases refers to stroke patients as they transition from hospital back into their homes and their communities, but also covers other neurology patients with acute rehabilitation needs. At the time of writing the ESD service in BaNES was comprised of physiotherapists, speech and language therapists, occupational therapists, a health psychologist (supported by a clinical neuropsychologist), specialist stroke nurses, a counsellor and an embedded stroke co-ordinator from the Stroke Association based in the same office, as well as administration support and management.

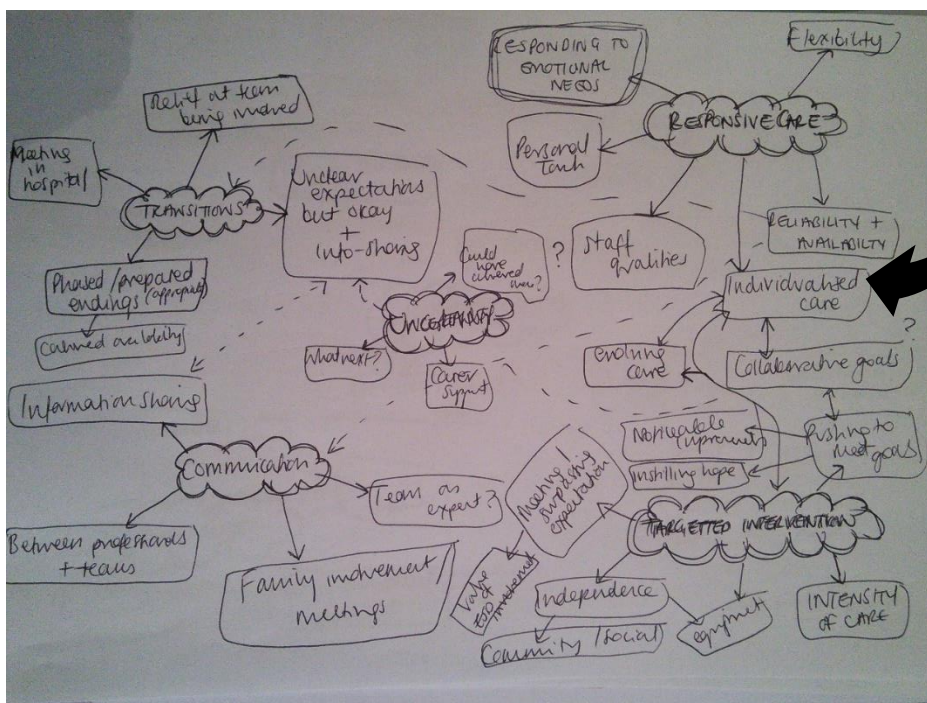
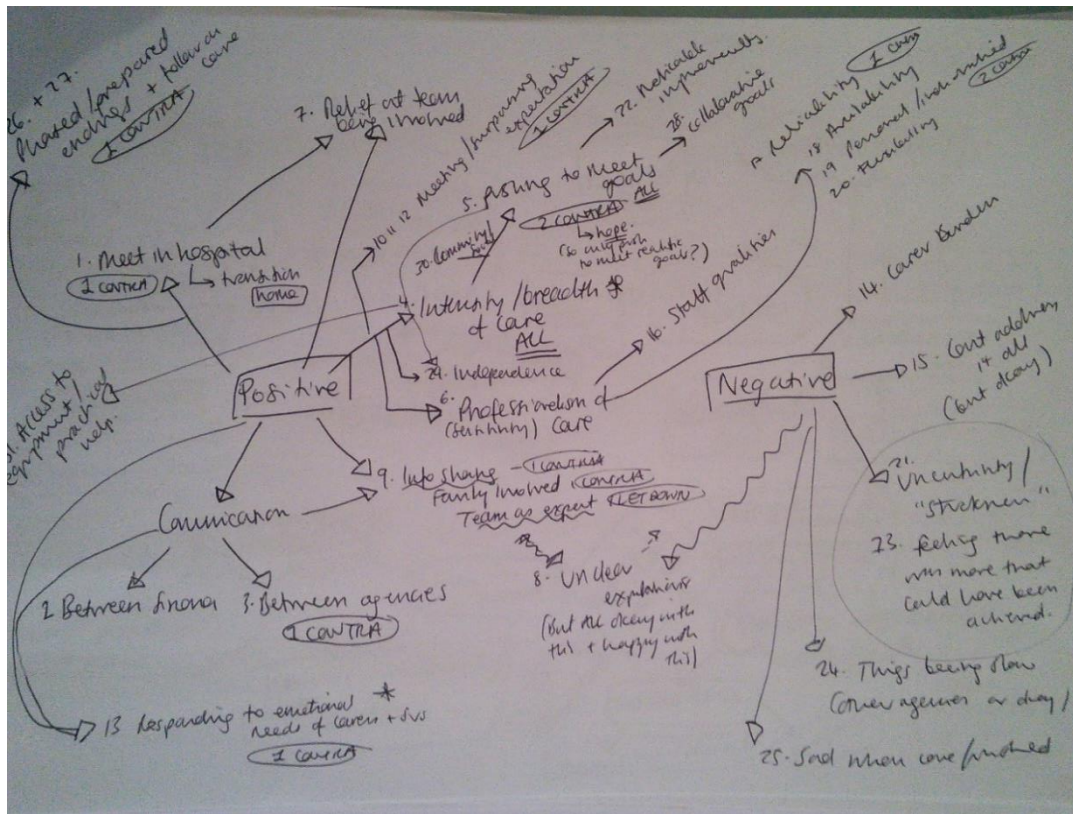
### *Participants*

Participants were patients or carers who had been discharged from the ESD service between one week and six months before the



## Appendix D: Examples of the Thematic Analysis Process









back at others  
Helen Wood.

Initial Ideas for Carer Themes

- Human touch / containment / responsive care
  - Responsiveness/availability
  - Availability/individualised
  - Collaborative/respectful
- Effective intervention
  - Quality/comprehensiveness/intensity/professionalism
  - Effective/increased independence/goal orientated/community engagement
  - Equipment/pestering other agencies
- Communication
  - Information sharing/meetings/family involvement
  - Other organisations
  - Non-verbal (emotional support??) ?
- Transitions
  - Inter-agency communication / relief?
  - Preparedness/phased approach
  - Appropriate timing/mutual
- Uncertainty
  - Carer support
  - Prognosis
  - Expectations

Carer burden

Going the extra mile

Pushing to achieve goals

Any 'failings' being reasonable/acceptable/expected (e.g. 'every stroke is different')

Emotional support

emotional commitment? (eg relief)

eg. negative not individualised  
how to pick into system?

→ list of recommendations for the time.

→ process of feeding back

→ how responded to.

② involving care / individualised.

As a point X mentioned Y → not in terms but important for time.

— Speak to details when you discuss  
eg. "this related to factors such as comprehensiveness ... etc"

## Appendix E: Recommendations

It is clear this is an excellent and well thought of service by patients and carers alike. Given the scope of this project to help improve the service I have pulled out all areas that could be tweaked based on service-user feedback. Many of the suggestions are about trying to ensure the great things you are doing already are available for all patients. Additionally, it is important for us to think about issues that may not be covered here (e.g. bereaved families, cultural issues, those who dis-engage) as this is a self-selecting sample it would be useful to think about any areas the staff team think may need addressing that were not highlighted by the interviews. I have also noted the areas that stood out as particularly strong in order for us to think about what we can learn from this and whether there might be something useful we can pull out as a recommendation for other ESD teams.

*Table of initial suggestions from meeting 28<sup>th</sup> January 2016*

Area	Suggestions	Next steps
<u>A Beginnings:</u> good information provision at the start – (some lack of clear expectations but consensus that this was not anxiety provoking nor a fault of the ESD team – rather due to lack of experience with stroke)	3. Protocol ‘beginnings’ to ensure the key areas highlighted by the themes as useful are always considered (e.g. helping to prepare for the move home – practical adjustments to the home; introducing the team and explaining what will happen next) 4. Touching on endings at the start - Explain how long the team will be involved for and how decisions are made to discharge patients	2. ESD team to discuss and create a protocol for the initial session(s) – this could be an induction checklist (MC has an example of this) to be simply ticked off and uploaded (or ticked off using the tablet live in the session) during the first session ( <b>EC, LM &amp; LD &amp; MC</b> )
<u>B Endings:</u> carers felt endings were phased and well prepared with detailed handovers being carried out where these were needed. However, although patients generally agreed with this, they found it	4. Implement discussions about endings at the start (see above) 5. Implement an endings meeting. This could include providing a leaflet (e.g. ‘Moving On’) detailing the impact of endings (using	4. ESD team to decide when might be the best timing for the endings meeting ( <b>EC &amp; LM</b> ) 5. Endings leaflet to be designed ( <b>MC &amp; LD</b> )

harder to say goodbye. This was for mixed reasons including feeling there was more that could have been done and for 60% feeling a sense of loss verging on abandonment. Additionally it was noted that feeling the service was ‘stretched’ disrupted the sense of security that was otherwise created – being clearer about endings and what will be available before then could be useful to address this	<p>previous literature and the current study) to help normalise and validate any difficult reactions. This would also be a good opportunity to go over relevant leaflets provided with the stroke pack at the start. The endings leaflet could also provide information about available services and contact information</p> <p>6. To provide a personalised ‘My next steps’ sheet where ongoing exercises and suggestions for community activities (stroke related or otherwise) are detailed. To photograph and upload to SystmOne (this can be a really simple sheet with just 2-4 headings – e.g. how can I continue to work on my rehabilitation at home - and a blank box to fill in suggestions)</p>	6. ‘My next steps’ sheet designed collaboratively with the ESD team ( <b>MC</b> can make suggestions and provide examples) ( <b>EC &amp; LM</b> )
<u>C Communication:</u> great use of imagery and written materials to support intervention work	1. Continue to use imagery, written info and photos to aid communication	1. Is there anything the ESD are doing here that might be useful to recommend to other ESD services? ( <b>EC &amp; LM</b> )
<u>D Information provision:</u> all carers felt this was done well but some patients felt that the information they needed was not always forthcoming	2. Ensuring information addresses individualised needs – using ongoing reviews to check if there are any questions or if information already provided needs to be tweaked to make it more affective/relevant for the individual	2. ESD team to consider how this could be implemented – is this part of the role of the case manager and if so could there be a formalised way to ensure this is covered (e.g. outstanding concerns and difficulties officially highlighted and addressed at a certain review point)? ( <b>EC &amp; LM</b> )
<u>E Team as expert:</u> highlighted by both carers and patients as a very useful part of the ESD teams involvement that helped	4. To continue to take a holistic approach to care, helping to advise and guide patients directly as well as signposting to resources	3. ESD team to consider modelling contacting services for patients where possible ( <b>EC &amp; LM</b> )



people to feel secure. This covered both communicating and researching available options as well as liaising directly with services on behalf of the family	<ul style="list-style-type: none"> <li>5. Where professional liaison is required it may be useful to model this for families (i.e. make phone calls with the family present) to help build their confidence to contact services independently</li> <li>6. To continue to have 'hand-over' meetings with follow-on services where relevant</li> </ul>	4. Is information from the ESD team made available to new services with the patient's permission? If so is this always done via a handover meeting? ( <b>EC &amp; LM</b> )
<u>F Dealing with uncertainty:</u> both carers and patients felt unsure about the future. For carers this was more around not knowing what the prognosis would be for their loved one and how they were supposed to keep supporting them. For patients this was more around being unprepared to face life post-stroke. Both groups acknowledged it would be impossible for the ESD team to provide concrete answers to these questions, but it was still difficult	<ul style="list-style-type: none"> <li>3. The 'Moving On' leaflet and personalised 'My next steps' sheet should help address some of these issues (see above)</li> <li>4. Support and training for ESD team staff members to help them consider how to manage difficult questions (e.g. acknowledging frustrations of not being able to know for sure, drawing out positives/progress, suggesting best ways to keep moving forwards – such as diet and exercise, signposting to additional support where relevant, psychological needs considered (see below))</li> </ul>	2. Psychology training provided bi-annually to ESD team staff to consider how to approach challenging questions and reflect on the impact uncertainty may have on them as professionals ( <b>LD</b> to provide, <b>MC</b> to help develop, <b>EC &amp; LM</b> to think about scheduling this in with <b>LD</b> and rest of team)
<u>G Carer/family involvement - information:</u> rated highly by carers and patients.	1. To continue to include key family members and carers in communications and invite them to review meetings	1. Is there anything the ESD are doing here that might be useful to recommend to other ESD services? ( <b>EC &amp; LM</b> )
<u>H Carer/family involvement – support:</u> nearly all carers noted being aware that they could seek support and half had accessed this and found it really useful. Patients less frequently noted that carers had received support themselves (perhaps due to nature of self-selecting patient	<ul style="list-style-type: none"> <li>4. To ensure going over the carers' leaflet and adjustment with carers is included in the 'induction checklist' (see point A)</li> <li>5. To check in 1:1 with carers/family members where possible</li> </ul>	<ul style="list-style-type: none"> <li>4. Induction checklist to be developed (see point A) (<b>EC, LM, LD &amp; MC</b>)</li> <li>5. Is there a place (e.g. review meetings) where a protocol or checklist would be useful to ensure carers perspectives are being sought independently from patient where possible? (<b>EC &amp; LM</b>)</li> </ul>

group for interviews = more independent = arguably less impact on carers). A small minority of carers and patients reported that family members were not offered any support but that this would have been really valuable – even just a conversation around adjustment.	6. Signposting carers to support options when their needs go beyond the scope of the ESD team	6. Including carer support options on the ‘moving on’ leaflet and/or the ‘my next steps’ sheet (see point B) <b>(EC, LM, LD &amp; MC)</b>
<u>I Individualised care:</u> rated really highly by all carers and patients	3. Continue to tailor interventions to suit individual’s needs, wants and interests 4. Think about ways to record how this is being considered	2. Is there anything the ESD team is doing that could be useful for other teams to know? <b>(EC &amp; LM)</b> 3. Would it be useful to consider re-visiting the ‘My journal’ paperwork to see if a summary could be useful for the team and/or the patient? One idea could be to have a simple page with summary info at the top then some summary sections (e.g. name, preferred name, family names, interests and needs) that the patient, carer and staff can add to (e.g. ‘Currently I am working on X by doing Y with Z; my goals are: X, Y, Z ; questions I have are: X, Y, Z’; social and community support that has been recommended to me is: X’) so that current information is centralised. ESD team to discuss if this would have any added value <b>(EC &amp; LM)</b>
<u>J Goals and instilling hope:</u> collaboratively working on goals was rated highly by both carers and patients. However, one carer	3. To continue to use GAS to collaboratively set and monitor goals 4. Consider how to instil hope in tricky cases – e.g. by working with patients to modify	2. ESD team to receive input from psychology around managing tricky situations and instilling hope / working with adjustment (see point F)

and two patients noted feeling somewhat de-motivated by the team at times.	goals to be more achievable, to use psychological training days to think about how to address these issues, to continue to encourage all patients to progress, however small that might be	
<u>K Psychological input (point H also relevant)</u> : nearly all patients and carers noted that the psychological needs of patients were considered. Where input was received this was rated as highly useful. Both patients who were not offered it felt it would have been useful. Of note both of these patients commented that the difficult moments were often later down the line, after the initial relief at having survived the stroke had passed. Going back to work was also a difficult time, as were endings (see point B)	<ol style="list-style-type: none"> <li>5. To continue to consider psychological needs of patients and carers</li> <li>6. For staff to receive regular training around how to assess and respond to psychological needs (e.g. to think about normal adjustment process versus distress requiring further input)</li> <li>7. For team to receive regular training on simple psychologically informed recommendations and resources they can share with patients and carers</li> <li>8. For psychological needs to continue to be addressed at the 6 month review – ensuring this is not just a tick box exercise looking at the PHQ9 and GAD7 but also questions asking how they have found the journey emotionally and how they think they are managing</li> <li>9. Literature about access to further support (e.g. talking to GP/LIFT) gone over at 6month review</li> </ol>	<ol style="list-style-type: none"> <li>3. Is there anything the ESD are doing here that might be useful to recommend to other ESD services? (EC &amp; LM)</li> <li>4. ESD team to receive input from psychology around assessing and responding to psychological distress (see point F and J)</li> <li>5. For ESD team to re-visit SNAP review process and see if there is a need to introduce a protocol where discussions (as well as measures) about psychological needs are included (EC &amp; LM)</li> </ol>
<u>L Interventions</u> : both carers and patients agreed that the interventions were incredibly thorough and broad. There was a consensus that the service went well	<ol style="list-style-type: none"> <li>1. Continue to provide high quality, intensive interventions addressing a broad spectrum of presenting difficulties</li> </ol>	<ol style="list-style-type: none"> <li>1. Is there anything the ESD team are doing that might be useful for other teams to consider? (EC &amp; LM)</li> </ol>

beyond expectation and the results were visible		
<u>M Improving Quality of Life (QoL):</u> nearly all patients and carers were agreed that the ESD team's input had markedly improved their QoL and much of this was focused on improving independence (e.g. ADLs) via improvements in physical ability, access to equipment and other resources and increased confidence	<ol style="list-style-type: none"> <li>1. Continue to work towards increasing patients independence – working with person-centred goals and ADLs</li> <li>2. Continue to provide useful equipment for short-term use and signpost to quality, affordable equipment for longer-term use</li> </ol>	<ol style="list-style-type: none"> <li>1. Is there anything the ESD team are doing that might be useful for other teams to consider? <b>(EC &amp; LM)</b></li> </ol>
<u>N Community and social engagement (related to point M):</u> where access to support groups and community activities was provided this was rated as extremely beneficial to the wellbeing of the patients. However, it appeared that this was not offered to everyone and some patients mentioned that they would have found this useful. 2 patients wanted groups for younger people	<ol style="list-style-type: none"> <li>3. To continue to inform patients and carers about the Stroke Association</li> <li>4. To inform all patients of available community and social activities – this may involve enquiring as to their interests and moving beyond stroke-related groups</li> <li>5. To consider online-forums as a form of social support (some patients reported being shy, immobile, younger than the people they expected would be attending the group)</li> </ol>	<ol style="list-style-type: none"> <li>3. To liaise with the Stroke Association about resources for younger stroke survivors and see if this is being offered to younger patients <b>(EC &amp; LM with Philippa)</b>. If it isn't, considering how this can be included</li> <li>4. To consider adding personalised support / activity recommendations to the 'My next steps' sheet and delegating this as a research responsibility to e.g. the case manager <b>(EC, LM &amp; MC)</b></li> </ol>
<u>O Ongoing service review:</u> in light of the findings of this analysis it would be useful to have ongoing feedback from patients and carers	<ol style="list-style-type: none"> <li>4. To consider how patient feedback is collated and used to inform practice</li> <li>5. To introduce an annual focus group</li> <li>6. Involvement of patients and carers in service development meetings / staff interviews etc.</li> </ol>	<ol style="list-style-type: none"> <li>4. Are current satisfaction forms collated and used at the moment? If so is this working well or is there anything we could work on tweaking? <b>(EC &amp; LM)</b></li> <li>5. Annual focus group in a less time-intensive format than the one recently carries out, e.g. where a volunteer / assistant takes charge of the organisation and summary? This could be various formats including the day format tried this year or a more</li> </ol>

		compact 1.5 hour group (1 for patients and 1 for carers) with key questions included. (EC & LM to discuss, MC happy to advise) 6. To what extent are patients and carers involved in service development, including hiring staff, at the moment? Could this be improved? (EC & LM to discuss, MC happy to advise)
<u>P Availability and reliability:</u> staff qualities in general were rated very highly by everyone. Availability and reliability in particular were reported to create a sense of safety	1. To continue to be available to patients and their families 2. To continue to work in a reliable way	1. Is there anything the ESD team are doing that might be useful for other teams to consider? (EC & LM)

#### Summary of what we have suggested about psychology training/support days:

- Sessions bi-annually to cover key issues including:
  - o educating patients and families about the psychological effects of stroke
  - o endings
  - o assessing psychological distress - when people need a psychology referral and when they don't
  - o simple emotion management techniques
  - o how to approach challenging questions (e.g. around needing answers/certainty)
  - o considering how to instil hope / openly discuss challenges in tricky cases
  - o reflecting on impact of work on staff and how to address this (e.g. use of supervision and co-workers)
- Allowing ESD team to email the psychologist with questions they have and support that would be useful in advance of the meetings

# ENDING WITH THE SERVICE

We recently asked service-users and carers about their experiences of working with the stroke team.

We found that it is common for people to feel worried when their time with the stroke team comes to an end.

For example, people said they found endings hard and upsetting, even when they thought they were prepared for it.

Reasons for this included missing the regular contact and support from staff and being uncertain about what might happen in the future.

So we have put together this leaflet to help you prepare for being discharged from the service.

in partnership with

Bath & North East  
Somerset Council



It is normal for people to be sad, worried and upset after a stroke. It can be hard to accept and adapt to the physical and social changes, especially when the stroke team stops visiting.

Being discharged from the Service means that you will no longer receive active care from the stroke team. However,

A **member of the team** will review you in:

Our **Stroke Coordinator, Philippa Gordon [T: 01225 831544]** will also contact you in:

We have also referred you to:

They should contact you in approximately:

For most people, adjusting to life after a stroke becomes easier over time. To help with this we recommend that you continue to work towards the goals that we set together:

- 1) Exercises:
- 2) Stroke group:
- 3) Hobbies/Activities:
- 4) .....

Engaging in other enjoyable activities may also help with managing worry or low mood. Whilst you may not be able to do all of the same activities as before your stroke, you should try and find things that are meaningful to you.

- 1) E.g., baking by myself is harder but I could cook with my children
- 2) E.g., reading is harder but I could listen to an audio book
- 3) .....
- 4) .....

-



If feelings of sadness or worry go on for a long time and start to affect your quality of life, it may be you are suffering with depression or anxiety.

This can be the case for the person who has had a stroke as well as those close to them, such as a husband, wife or partner.

If you feel unable to manage this by yourself, it may be that you need some additional support.

If so, talk to your GP. They might suggest a talking therapy or an antidepressant. Their number is:

## **Other useful contacts:**

### **Stroke Association:**

T 0303 3033 100 [www.stroke.org.uk](http://www.stroke.org.uk)



### **BANES Talking Therapies Service:**

T: 01225 675150 <https://iapt-banes.awp.nhs.uk/>



### **BANES Carers Centre:**

T: 0800 0388 885 <https://banescarerscentre.org.uk>



### **Wellbeing College:**

T: 01225 831820 [wellbeingcollegebanes.co.uk](http://wellbeingcollegebanes.co.uk)





## **Appendix G: Instructions for Authors – Journal of Behavior Therapy and Experimental Psychiatry**

### **TYPES OF CONTRIBUTIONS**

The Journal welcomes contributions to the understanding and treatment of psychopathology. Such contributions may stem from various theoretical perspectives, such as learning theory, cognitive science, social psychology, developmental psychology, etc. The Journal primarily focuses on experimental tests of psychological approaches to psychopathology, though contributions from medicine, biology, sociology, or epidemiology may be published. The same holds for non-experimental approaches, which may occasionally be published if deemed relevant for the field of experimental psychopathology. Papers to be published generally focus on:

- Theoretically or clinically relevant differences between specific patient groups and other groups, if experimentally tested;
- Mechanisms that cause, perpetuate or reduce disorders;
- Diagnostic or therapeutic procedures

Participants in the study may be patients, non-patients or animals, depending on the relevance of the subject characteristics for the question to be answered. In line with the aims of the Journal, priority is given to studies

- 1) using experimental methods with
- 2) data derived from patient samples rather than analogue groups.

Some research questions are best answered in non-patients. This should be evident from the nature of the questions or hypotheses.

Clinical trials (RCTs and others) should be registered in an official trial register and the registration number should be reported. These studies should include a flow diagram according to the most recent CONSORT guidelines and a CONSORT checklist should accompany the submission. See External link <http://www.consort-statement.org> for the guidelines and forms.

Studies testing hypotheses on characteristics of a disorder should not only include a non-patient control group, but also an appropriate clinical control group, to assess the specificity of the effect. We cannot guarantee acceptance of studies missing an appropriate clinical control group.

Case studies, open trials, and pilot studies may be considered for publication in the Journal if they are unusually innovative and important for the field of experimental psychopathology.

Consecutive case series with appropriate designs (i.e., contrasting at least two conditions; e.g. multiple baseline design, ABAB designs, etc.) and appropriate statistical analyses are considered for publication.

Replications are essential in science and are, to the present editor's opinion, often undervalued. Short reports of attempts to replicate experimental studies, whether successful, or failed, and whether applied or fundamental, are considered for publication, if appropriately powered. The maximum number of words is 2500 for these reports.

Paper length. Regular manuscripts should not exceed 5000 words (15-20 pages) of body text. Short reports should have a maximum of 2500 words. All submissions will first be screened on the degree to which they match the Aims and Scope of the Journal.

## ETHICS IN PUBLISHING

Please see our information pages on [Ethics in publishing](#) and [Ethical guidelines for journal publication](#).

### ***Conflict of interest***

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also <http://www.elsevier.com/conflictsofinterest>.

A declaration of interest is obligatory and should list fees and grants from, ownership of, employment by, and any other financial or other close relationship with an organization whose interests may be affected by the publication of the paper, even if the authors feel that there is no conflict. The declaration should hold for all authors. If there is no interest to be declared, the authors should explicitly state this.

### **ROLE OF THE FUNDING SOURCE**

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

### ***Funding body agreements and policies***

Elsevier has established a number of agreements with funding bodies which allow authors to comply with their funder's open access policies. Some funding bodies will reimburse the author for the Open Access Publication Fee. Details of [existing agreements](#) are available online.

### ***References***

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

### ***Formatting requirements***

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

### ***Figures and tables embedded in text***

Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file. The corresponding caption should be placed directly below the figure or table.

### **PEER REVIEW**

This journal operates a double blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a

minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. [More information on types of peer review.](#)

## ARTICLE STRUCTURE

### ***Subdivision - numbered sections***

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

### ***Introduction***

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

### ***Material and methods***

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

### ***Results***

Results should be clear and concise.

### ***Discussion***

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

### ***Conclusions***

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

### ***Appendices***

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

## ESSENTIAL TITLE PAGE INFORMATION

- ***TITLE.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- ***AUTHOR NAMES AND AFFILIATIONS.*** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- ***CORRESPONDING AUTHOR.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. ENSURE THAT THE E-MAIL ADDRESS IS GIVEN AND THAT CONTACT DETAILS ARE KEPT UP TO DATE BY THE CORRESPONDING AUTHOR.
- ***PRESENT/PERMANENT ADDRESS.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did

the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### **ABSTRACT**

A concise and factual abstract is required. The abstract should be structured, using the following headings: *Background and Objectives; Methods; Results; Limitations; Conclusions*. Maximum length is 250 words, including headings. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

#### ***Highlights***

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view [example Highlights](#) on our information site.

#### **KEYWORDS**

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### ***Abbreviations***

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

#### **FIGURES**

##### ***Figure captions***

Ensure that each illustration has a caption. A caption should comprise a brief title (NOT on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

#### **TABLES**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

## Appendix H: HRA Ethical Approval Letter



Miss Megan Cowles  
University of Bath 6 West  
Claverton Down  
Bath  
BA2 7AY

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

07 July 2016

Dear Miss Cowles,

### Letter of **HRA Approval**

Study title:	Does state-anxiety lead to increased state-paranoia in people with paranoid psychosis? An experimental investigation
IRAS project ID:	201330
Protocol number:	N/A
REC reference:	16/WA/0162
Sponsor	University of Bath

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

## Appendix I: Measures

### Paranoia Checklist (modified)

Many people have thoughts, worries, or suspicions that others may be trying to upset them. It is a common experience, just as people can sometimes feel anxious or low in mood. Below are listed some of the thoughts that people report. For each one please indicate how strongly you believe it.

0	1	2	3	4
<b>Do not believe it</b>	<b>Believe it a little</b>	<b>Believe it somewhat</b>	<b>Believe it a lot</b>	<b>Absolutely believe it</b>
1. 'I need to be on my guard against others.'				
0	1	2	3	4
2. 'There might be negative comments being circulated about me.'				
0	1	2	3	4
3. 'Others deliberately try to irritate me.'				
0	1	2	3	4
4. 'I might be being observed or followed.'				
0	1	2	3	4
5. 'Others are trying to make me upset.'				
0	1	2	3	4
6. 'Others communicate about me in subtle ways'				
0	1	2	3	4
7. 'Others look at me critically.'				
0	1	2	3	4
8. 'Others might be hostile towards me.'				
0	1	2	3	4

9. 'Bad things are being said about me behind my back.'

0                      1                      2                      3                      4

10. Someone (or something) I know has bad intentions towards me'

0                      1                      2                      3                      4

11. 'I have a suspicion that someone (or something) has it in for me.'

0                      1                      2                      3                      4

12. 'Others would harm me if given an opportunity.'

0                      1                      2                      3                      4

13. 'Someone (or something) I don't know has bad intentions towards me.'

0                      1                      2                      3                      4

14. 'There is a possibility of a conspiracy against me.'

0                      1                      2                      3                      4

15. 'Others are laughing at me.'

0                      1                      2                      3                      4

16. 'I am under threat from others.'

0                      1                      2                      3                      4

17. 'I can detect coded messages about me in the press/TV/radio'

0                      1                      2                      3                      4

18. 'My actions and thoughts might be controlled by others.'

0                      1                      2                      3                      4

## Psychotic Symptoms Rating Scale – Section B: Scoring Sheet

Note items from PC to enquire about here:

	SCORE
1. AMOUNT OF PREOCCUPATION	<input type="text"/>
2. DURATION OF PREOCCUPATION	<input type="text"/>
3. CONVICTION	<input type="text"/>
4. AMOUNT OF DISTRESS	<input type="text"/>
5. INTENSITY OF DISTRESS	<input type="text"/>
6. DISRUPTION	<input type="text"/>
<b>TOTAL DELUSIONS SCORE</b>	<input type="text"/>



## **Psychotic Symptoms Rating Scale – Section B: Interview Schedule**

### **1. Amount of preoccupation with belief**

#### **Probing questions**

*Over the last week, how much time have you spent thinking about your beliefs about [insert client's beliefs]?*

#### Scoring criteria:

- 0 No delusions, or delusions which the interviewee thinks about less than once a week.
- 1 Interviewee thinks about beliefs at least once a week.
- 2 Interviewee thinks about beliefs at least once a day.
- 3 Interviewee thinks about beliefs at least once an hour.
- 4 Interviewee thinks about delusions continuously or almost continuously.

### **2. Duration of preoccupation with delusions**

#### **Probing questions**

*When you have thought about any of your beliefs (i.e. [insert interviewee's belief]) over the last week, how long do they tend to stay in your mind? - Few seconds/minutes/hours, etc.?*

#### Scoring criteria:

- 0 No delusions
- 1 Thoughts about beliefs last for a few seconds, fleeting thoughts
- 2 Thoughts about delusions last for several minutes
- 3 Thoughts about delusions last for at least one hour
- 4 Thoughts about delusions usually last for hours at a time

### **3. Conviction**

#### **Probing questions**

*At the moment, do you have any doubts about any of your beliefs, for example do you sometimes wonder whether they are real or not? How much do you believe in [insert beliefs]? Can you estimate this on a scale from 0 – 100, where 100 means that you are totally convinced and 0 means that you are not convinced at all?*

#### Scoring criteria:

- 0 No conviction at all
- 1 Very little conviction in reality of beliefs, less than 10%
- 2 Some doubts relating to conviction in beliefs, between 10-49%
- 3 Conviction in belief is very strong, between 50 – 99%
- 4 Conviction is 100%

### **4. Amount of Distress**

#### **Probing questions**

*Have your beliefs about [insert interviewee's beliefs] caused you distress over the last week?  
How much of the time have they caused you distress over the last week?*

Scoring criteria:

- 0 Beliefs never cause distress
- 1 Beliefs cause distress on the minority of occasions.
- 2 Beliefs cause distress on less than 50 % of occasions
- 3 Beliefs cause distress on the majority of occasions between 51-99% of time
- 4 Beliefs always cause distress when they occur

## **5. Intensity of Distress**

### **Probing questions**

*Over the last week, when you have felt distressed by your beliefs about [insert interviewee's beliefs] how severe does this feel?" Have you felt slightly distressed, moderately distressed etc.*

Scoring criteria:

- 0 No distress
- 1 Beliefs cause slight distress
- 2 Beliefs cause moderate distress
- 3 Beliefs cause marked distress
- 4 Beliefs cause extreme distress, couldn't be worse

## **6. Disruption to life caused by beliefs**

### **Probing questions**

*In what way have your beliefs caused disruption for you over the last week?  
In what way have they stopped you working or carrying out a day-time activity?  
In what way have they interfered with your relationships with family or friends?  
In what way have they interfered with your ability to look after yourself?*

Scoring criteria:

- 0 No disruption to life, able to maintain independent living with no problems in daily living skills. Able to maintain social and family relationships (if present)
- 1 Beliefs cause minimal amount of disruption to life, e.g. interferes with concentration although able to maintain social and family relationships and independent living.
- 2 Beliefs cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The interviewee is not in hospital although may live in supported accommodation or receive additional help with ADLs.
- 3 Beliefs cause severe disruption to life so that hospitalisation is usually necessary. The interviewee is able to maintain some daily activities, self-care and relationships whilst in hospital or supported accommodation but severe disruption present in ADLs and relationships.
- 4 Beliefs cause complete disruption of daily life requiring hospitalisation. The interviewee is unable to maintain any daily activities and social relationships. Self-care is severely disrupted.

### Forms of Self-Criticism and Self-Reassurance Scale: Short Version

When things go wrong in our lives we sometimes have *negative and self-critical thoughts and feelings*. These may take the form of feeling worthless, useless or inferior etc. However, people can also try to be supportive of themselves. Below are a series of thoughts and feelings that people sometimes have. Read each statement carefully and circle the number that best describes how much each statement is true for you.

0	1	2	3	4
<b>Not at all like me</b>	<b>A bit like me</b>	<b>Moderately like me</b>	<b>Quite a bit like me</b>	<b>Extremely like me</b>

#### When things go wrong for me...

1. I am easily disappointed with myself

0	1	2	3	4
---	---	---	---	---

2. I am able to remind myself of positive things about myself

0	1	2	3	4
---	---	---	---	---

3. There is a part of me that feels I am not good enough

0	1	2	3	4
---	---	---	---	---

4. I still like being me

0	1	2	3	4
---	---	---	---	---

5. I have become so angry with myself that I want to hurt or injure myself

0	1	2	3	4
---	---	---	---	---

6. I have a sense of disgust with myself

0	1	2	3	4
---	---	---	---	---

7. I can still feel lovable and acceptable

0 1 2 3 4

8. I find it easy to like myself

0 1 2 3 4

9. I remember and dwell on my failings

0 1 2 3 4

10. I think I deserve my self-criticism

0 1 2 3 4

11. I encourage myself for the future

0 1 2 3 4

### Brief State Measure

Please rate how much each statement applies to you **AT THE MOMENT** by making a mark on each line:

1 I feel ashamed

Not at all  
true

\_\_\_\_\_

Extremely  
true

2 I remember and dwell on my failings

Not at all  
true

\_\_\_\_\_

Extremely  
true

3 I am able to remind myself of positive things about myself

Not at all  
true

\_\_\_\_\_

Extremely  
true

4 I feel sad

Not at all  
true

\_\_\_\_\_

Extremely  
true

5 I have a sense of disgust with myself

Not at all  
true

\_\_\_\_\_

Extremely  
true

6 I feel relaxed

Not at all  
true

\_\_\_\_\_

Extremely  
true

7 I have become so angry with myself that I want to hurt or injure myself

Not at all  
true

\_\_\_\_\_

Extremely  
true

8 I feel irritated

Not at all  
true

\_\_\_\_\_

Extremely  
true

9 I feel calm

Not at all true	_____	Extremely true
	10 <u>Strangers and friends look at me critically</u>	
Not at all true	_____	Extremely true
	11 <u>I still like being me</u>	
Not at all true	_____	Extremely true
	12 <u>I am distressed by thoughts of others wishing me harm</u>	
Not at all true	_____	Extremely true
	13 <u>I need to be on my guard against others</u>	
Not at all true	_____	Extremely true
	14 <u>People are trying to make me upset</u>	
Not at all true	_____	Extremely true
	15 <u>I feel happy</u>	
Not at all true	_____	Extremely true
	16 <u>I think I deserve my self-criticism</u>	
Not at all true	_____	Extremely true
	17 <u>I feel anxious</u>	
Not at all true	_____	Extremely true

## **Appendix J: Study scripts**

### **The Brief Relaxation Script**

This script was used before the memory recall and compassionate imagery segments of the protocol.

“Please sit down comfortably on your chair. Now close your eyes and begin to breathe more calmly. Notice the air as it passes in and out over the skin of your mouth or nostrils. You can feel your body moving to let the breath in and out. Give yourself permission to become more and more relaxed. Feel your feet resting on the floor, your legs relaxing into your seat. Notice any tension in your muscles and let it go. Feel your body relaxing into your seat. You are breathing calmly and feeling deeply relaxed.”

### **The Memory Recall Script**

The following script was a guide that would be adapted depending on the memory being recalled.

“Now bring back into mind the memory you just described [include brief description of anxious or neutral memory]. Where are you? What do you see? What are you doing? Who is there with you? What is happening? How do you look at this moment? What can you see? Can you describe what you hear? What can you smell? What are you looking at? What thoughts are running through your mind? What emotions are coming up for you? How does your body feel? How vivid does this memory feel from 0 – 100, with zero meaning you are not remembering anything and 100 meaning that the memory is so vivid you feel like you are back there again.”

The memory recall was terminated by instructing the participant to become aware of their body on the seat and the sounds in the room around them before opening their eyes.

### **The Compassionate-Colour Imagery Script**

This script was modified from an online resource: [www.actwithcompassion.com](http://www.actwithcompassion.com)

“I would like you to bring to mind the image of a colour. This should be a colour that you associate with compassion, a colour that conveys some sense of warmth and kindness. It might only be a fleeting sense of colour or you may have more than one colour. Sometimes imagining an object of the same colour can help to bring the colour more vividly to our minds. When you are ready, imagine your compassionate colour surrounding you, perhaps like a forcefield protecting you. Focus on this colour as having wisdom, strength and warmth, with a

key quality of total kindness. Then, imagine your compassionate colour entering through your heart area and slowly through your body. Know that this colour knows everything about you, your past, your thoughts, and it accepts you wholly and completely as you are. Imagine this colour like a mist or light just flowing through you. Now, as you imagine the colour flowing through you focus on the feeling that the sole purpose of this colour is to help you, to strengthen you and support you. The colour conveys compassion for you, it cares for you, and wants you to feel good and be without worries. If any resistance, blocks or barriers arise just recognise these as ‘distractions’ and gently but firmly go back to focusing on your compassionate colour. This colour is deeply committed to you, it wants you to feel good and experience joy. It conveys so much warmth you can even feel the warmth. Your colour is wise, strong, accepting and deeply committed to you. Now take a moment to be with your colour and picture it as well as you can, perhaps saying the name of this colour silently to yourself, knowing that you can come back to your compassionate colour whenever you want to. Now just notice your body on the seat and bring your attention to the room around you. Please open your eyes”



## **Appendix K: Power Analyses**

Power analyses were carried out using G\*Power software, version 3.1.5 (Faul, Erdfelder, Buchner, & Lang, 2009).

### **A Priori: Independent Samples**

#### ***Independent groups t-test***

The sample size needed for an independent groups t-test based on a significance level of .05, power of .8 and a predicted effect size of .66 was calculated to be 76 (38 in each group). The estimated effect size was based on Lincoln et al.'s 2010 study; they found an effect size of .66 for paranoia difference between groups.

### **Post-hoc: Repeated Measures**

#### ***Paired t-test (hypothesis one)***

The study had .99 power to detect the observed difference in paranoia from pre-to-post the anxious condition, based on a significance level of .05, a sample of 21 and an effect size of -1.07.

The study was powered between .9 - 1 to detect differences in all other variables (anxiety, negative-affect, positive-affect) explored from pre-to-post the anxious condition (significance .05, sample 22, effect size as per Table 3.3). However, power was .1 - .6 to detect differences from pre-to-post the neutral condition as the change in these variables was less notable.

#### ***Regression (hypothesis two and four)***

The study had .83 power to detect a significant regression effect of anxiety on paranoia, based on significance level of .05, a sample of 21, an effect size of .45 (Table 3.4) and one predictor.

Based on the same parameters, the study had .93 power to detect a significant regression effect of negative-affect on paranoia (effect size .64), and .5 power to detect a significant regression effect of positive-affect on paranoia (effect size .2).

### ***Multiple regression (hypothesis three)***

The study had .96 power to detect a significant regression effect of anxiety and negative-affect on paranoia, based on significance level of .05, a sample of 21, an effect size of .92 (Table 3.4) and two predictors.

### **Summary**

#### ***Independent Groups***

This study was underpowered to use parametric tests to explore differences between independent groups. As such, this data was explored using non-parametric tests (see appendix V).

#### ***Repeated-Measures***

This study was powered to detect differences from pre-to-post the anxious condition, but was under powered to detect differences from pre-to-post the neutral condition. The study was powered to detect a regression effect of anxiety, negative-affect and anxiety & negative-affect on paranoia. However, this study was under powered to detect a regression effect of positive-affect on paranoia.

## **Appendix L: Independent Groups Data**

This section should be read in conjunction with the main research project. It provides analysis of independent groups data with a brief discussion.

### **Modifications to Method**

#### **Design**

This was an independent groups experimental design. The protocol was the same as described in the main research project, although only data for the first condition that participants completed was included.

#### **Participants**

The 22 participants were aged between 20 – 60 years-old ( $M = 32.82$ ;  $SD = 10.72$ ); those in the anxious condition were aged between 20-48 years-old ( $N = 11$ ;  $M = 32$ ;  $SD = 10.39$ ) and those in the neutral condition were aged between 20-60 years old ( $N = 11$ ;  $M = 33.64$ ;  $SD = 11.49$ ). The time since first recorded psychotic episode ranged from 0.5 – 27 years ( $N = 22$ ;  $M = 9.13$ ;  $SD = 9.22$ ); those in the anxious condition ranged from 0.8-27 years since first episode ( $N = 11$ ;  $M = 9.8$ ;  $SD = 10.01$ ) and those in the neutral condition ranged from 0.5-26 years ( $N = 11$ ;  $M = 8.5$ ;  $SD = 8.79$ ). There were no significant differences between the two groups in age (Mann-Whitney  $U = 57$ ,  $p = .89$ ), or time since first recorded episode (Mann-Whitney  $U = 65$ ,  $p = .8$ ). Please see Table L.1 for a summary of additional demographic information. When analysed using chi-square test of independence, there were no significant differences in any variable apart from gender,  $X^2(1) = 4.7$ ,  $p = .03$ . There were more men in the neutral group (81.8%) and more women in the anxious group (63.6%).

Table L.1

*Demographic Information*

	Demographic	Anxious		Neutral		Total	
		Freq	%	Freq	%	Freq	%
<b>Gender</b>	<i>Female</i>	7	63.6	2	18.2	9	41
	<i>Male</i>	4	36.4	9	81.8	13	59.1
<b>Ethnicity</b>	<i>White British</i>	11	100	9	81.8	20	91
	<i>White Other</i>	0	0	1	9.1	1	4.5
	<i>White &amp; Black Caribbean British</i>	0	0	1	9.1	1	4.5
<b>Employment Status</b>	<i>Unemployed</i>	6	54.6	8	72.7	14	63.6
	<i>Employed</i>	1	9.1	2	18.2	3	13.6
	<i>Part-time volunteer</i>	2	18.2	1	9.1	3	13.6
	<i>Student</i>	2	18.2	0	0	2	9.1
<b>Marital Status</b>	<i>Single</i>	8	72.7	8	72.7	16	72.7
	<i>Cohabiting</i>	3	27.3	2	18.2	5	22.7
	<i>Widowed</i>	0	0	1	9.1	1	4.5
<b>Primary Diagnosis</b>	<i>Paranoid schizophrenia</i>	5	45.5	5	45.5	10	45.5
	<i>Non-organic psychosis</i>	3	27.3	4	36.4	7	31.8
	<i>Drug induced psychosis</i>	2	18.2	0	0	2	9.1
	<i>Schizotypal</i>	0	0	1	9.1	1	4.5
	<i>Schizoaffective</i>	0	0	1	9.1	1	4.5
	<i>Bipolar with psychotic symptoms</i>	1	9.1	0	0	1	4.5
<b>Psychiatric Medication</b>	<i>Anti-psychotics</i>	8	72.7	9	81.8	17	77
	<i>Anti-depressants</i>	2	18.2	4	36.4	6	27.3
	<i>Anxiolytics</i>	1	9.1	3	27.3	4	18.2
	<i>Insomnia medication</i>	3	27.3	0	0	3	13.6
	<i>Alcoholism medication</i>	0	0	1	9.1	1	4.5
	<i>None</i>	2	18.2	1	9.1	3	13.6

Note: 'Freq' = frequency; '%' = percentage.

## Statistical Analysis Plan

Due to small sample sizes, non—parametric Mann-Whitney U tests were used to see if there were differences in variables of interest between the anxious and neutral conditions at baseline and after the experimental condition. Spearman’s rank order correlations were used to see if paranoia after the experimental condition was correlated with levels of anxiety to a greater degree than other affective states, and whether trait-paranoia was associated with state-paranoia, after the experimental condition.

## Results

### Baseline Group Differences Check

Mann-Whitney U tests indicated that there were no significant differences between the anxious and neutral groups on any baseline measure (Table L.2).

Table L.2

*Mann-Whitney U test results for differences between groups at baseline*

Variable	N	Mean Rank Neut	Mean Rank Anx	U	p
<b>PC</b>	$n_1 = n_2 = 11$	11.32	11.68	62.5	.898
<b>PSYRATS-B</b>	$n_1 = n_2 = 11$	10.09	12.91	76	.332
<b>T1 Paranoia</b>	$n_1 = n_2 = 11$	10.14	12.86	75.5	.332
<b>T1 Distress</b>	$n_1 = n_2 = 11$	10.05	12.95	76.5	.3
<b>T1 Anxiety</b>	$n_1 = n_2 = 11$	10.91	12.09	67	.699
<b>T1 Negative</b>	$n_1 = n_2 = 11$	11.27	11.73	63	.898
<b>T1 Positive</b>	$n_1 = n_2 = 11$	12.41	10.59	50.5	.519

*Note: T1 = pre-experimental condition; Neut = neutral group; Anx = anxious group*

### Manipulation Check

Mann Whitney U tests showed that levels of anxiety and negative-affect were significantly greater after the experimental condition in the anxious group compared to the neutral group; positive-affect was significantly lower (Table 3). This demonstrates that the anxious condition led to greater anxiety than the neutral condition (Figure 1). However, as negative-affect and positive-affect were also significantly different between the groups after the experimental condition, these were considered in further analyses.



Figure L.1. Mean Anxiety Ratings at Each Time Point

### Hypothesis One: The Anxious Condition will lead to Greater Paranoia than the Neutral Condition

Paranoia was significantly greater after the experimental condition in the anxious group compared to the neutral group (Table L.3; Figure L.2), supporting hypothesis one. There was no significant difference between the groups in levels of paranoia-related distress after the experimental condition.

Table L.3

*Mann-Whitney U test results for differences between groups after experimental condition*

Variable	N	Mean Rank Neut	Mean Rank Anx	U	p
<b>T2 Paranoia</b>	n <sub>1</sub> = n <sub>2</sub> = 11	7.27	15.73	107	.001***
<b>T2 Distress</b>	n <sub>1</sub> = n <sub>2</sub> = 11	9.68	13.32	80.5	.193
<b>T2 Anxiety</b>	n <sub>1</sub> = n <sub>2</sub> = 11	6.09	16.91	120	<.001***
<b>T2 Negative</b>	n <sub>1</sub> = n <sub>2</sub> = 11	8.36	14.64	95	.023*
<b>T2 Positive</b>	n <sub>1</sub> = n <sub>2</sub> = 11	16.18	6.82	9	<.001***

*Note: T2 = post-experimental condition; Neut = neutral group; Anx = anxious group*

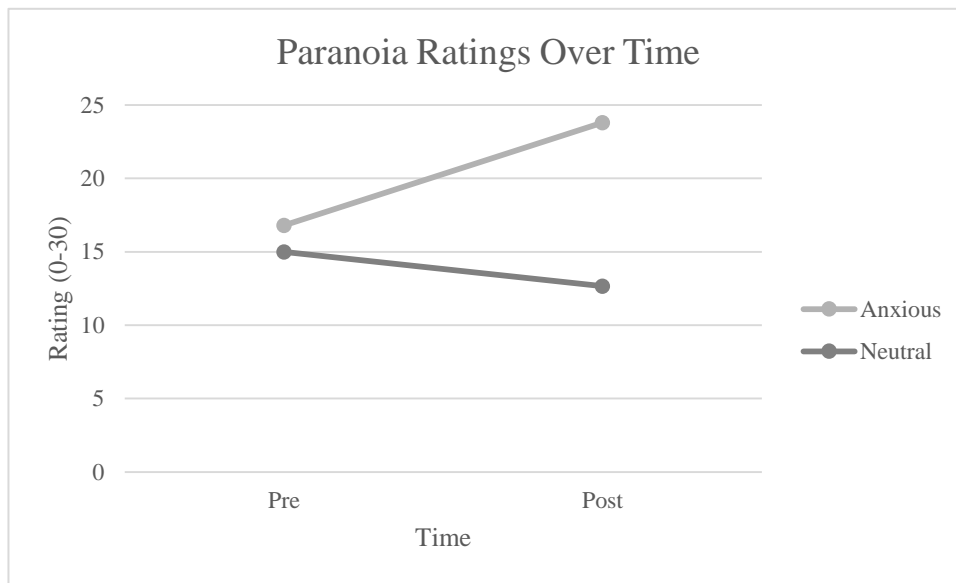


Figure L.2. Mean Paranoia Ratings at Each Time Point

### **Hypothesis Two: State-Anxiety will Significantly Predict State-Paranoia after the Experimental Condition**

Given the nature of the statistical tests used, it was not possible to test for a predictive relationship between anxiety and paranoia, or to conduct partial correlations controlling for influences from other variables. However, state-anxiety was found to be significantly positively correlated with state-paranoia after the experimental conditions ( $r_s = .71$ ;  $N = 22$ ;  $p < .001^{***}$ ). This lends some support to hypothesis two, showing that levels of state-anxiety were associated with levels of state-paranoia.

### **Hypothesis Three: State-Anxiety will predict State-Paranoia Over and Above Other Variables**

Negative-affect was significantly positively correlated to state-paranoia ( $r_s = .71$ ;  $N = 22$ ;  $p < .001^{***}$ ), and positive-affect was significantly negatively correlated to state-paranoia ( $r_s = -.75$ ;  $N = 22$ ;  $p < .001^{***}$ ) after the experimental condition. This does not support hypothesis three, showing that greater levels of negative-affect and lower levels of positive-affect were also associated with greater levels of state-paranoia. Therefore, state-anxiety was not the only correlate of state-paranoia, nor was it the strongest.

However, all three of the independent variables were significantly associated with each other (negative-affect and state-anxiety [ $r_s = .65$ ;  $N = 22$ ;  $p < .001^{***}$ ], state-anxiety and positive-affect [ $r_s = -.82$ ;  $N = 22$ ;  $p < .001^{***}$ ], positive-affect and negative-affect [ $r_s = -.69$ ;  $N = 22$ ;  $p < .001^{***}$ ]), suggesting collinearity. With this in mind, it is not possible to delineate the unique relationships between each of the independent variables and the dependent variable as they are strongly related to each other.

#### **Hypothesis Four: Trait Paranoia Will Predict State-Paranoia after the Experimental Conditions**

Trait paranoia as measured by the PSYRATS-B was significantly positively correlated with state-paranoia after the experimental condition ( $r_s = .43$ ;  $N = 22$ ;  $p = .048^*$ ). Trait paranoia was not associated with state-paranoia at baseline ( $r_s = .24$ ;  $N = 22$ ;  $p = .275$ ). This lends some support to hypothesis four, although it was not possible to test for a predictive relationship.

#### **Discussion**

The independent groups data found similar results to the repeated measures data. The first hypothesis; that the anxious-mood induction would lead to greater state-paranoia than the neutral-mood induction, was supported. The second hypothesis; that state-paranoia would be predicted by state-anxiety after the anxious condition, could not be tested, but a significant positive correlation was found. The third hypothesis, that state-anxiety would predict state-paranoia to a greater extent than other affective states after the experimental conditions, could not be tested, but state-anxiety was not the only significant correlate of state-paranoia. The anxious condition led to significantly greater levels of anxiety but also led to significantly greater levels of negative-affect and led to significantly lower levels of positive-affect. Results showed that levels of negative- and positive-affect were also significantly correlated with state-paranoia. Apparent collinearity between the three independent variables means it was not possible to draw conclusions about unique relationships between each of these variables and state-paranoia. The fourth hypothesis, that higher trait-paranoia would predict higher state-paranoia after the experimental conditions, could not be tested, but trait paranoia was significantly associated with state-paranoia after the experimental conditions.



## **Implications**

Implications are largely similar to those outlined in the main research project.

## **Limitations**

An important limitation of this study was that gender was not evenly distributed between the two groups, meaning that differences between the groups on outcomes could feasibly have been due to gender rather than the independent variables. Given the theoretical basis for the hypotheses tested here and the lack of evidence that gender has a role in the link between anxiety and paranoia, it is unlikely that this is the case. However, it cannot be ruled out. It was not possible to control for gender in the analyses conducted here due to the small sample size.

Issues raised about the measure of affect used in this study are especially pertinent here given the strong associations between all three affective states. Future studies would benefit from developing more affect-specific state-measures that can be completed in a short timeframe.

## **Conclusions**

Independent groups data largely supported the results found in the repeated measures data. State-paranoia was greater after the anxious condition compared to the neutral condition. Anxiety was associated with state-anxiety after the experimental conditions. However, negative-affect and positive-affect were also significantly associated with state-paranoia. Trait paranoia was associated with state-paranoia after the experimental conditions.

Although the independent groups design used in this appendix overcomes some of the limitations outlined in the main research project, it was under-powered to allow statistical analyses to directly test the hypotheses. However, it is an interesting pilot study for future research to consider replicating with some modifications.